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Looking inside the face

experiences of living with an accidentally acquired facial disfigurement and its perceived impact on identity; Interpretative phenomenological analysis

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Looking inside the face – experiences of living with an accidentally acquired facial disfigurement and its perceived impact on identity; Interpretative phenomenological analysis

by

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Contents

Abstract

This thesis focuses on women who have accidentally acquired a facial disfigurement and their perceptions, perspectives, and experiences of identity. This research aims to add to this overlooked topic within counselling psychology through the use of interpretative phenomenological analysis (IPA). Adopting a phenomenological approach allows for in-depth exploration of the experience of identity after accidentally acquiring a facial disfigurement.

Semi-structured interviews were conducted with six female participants who had accidentally acquired a facial disfigurement in the past one to five years. Transcripts were then coded and analysed to produce emergent themes, which were used to construct three superordinate themes with accompanying subthemes: 'Shattered self' included the subthemes 'Person behind the face', 'Aftermath', 'Loss of self', and 'Outsider after once belonging'. The second superordinate theme was named 'Front seat of identity' and included the subthemes 'Expressionless', 'Identifying with exclusion', and 'Separation of mind and body'. Finally, 'Sculpted self' encompassed 'Made peace with pain', 'Touching death', and 'Integration of self'.

Insight gathered in this study is aimed to help understand how the face links to one's identity through the experience of accidentally acquiring a facial disfigurement. This research highlighted key psychological difficulties experienced by this group including shame, loss of the old self, post-traumatic stress disorder, stages of grief, a sense of injustice, social exclusion, complexities of integrating the old and new identity, loneliness and social isolation. In understanding the unique, specific needs of this group, we can begin to form tailored psychological support.

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Introduction

Recovering from facial injuries is, in the end, about how well you can communicate with the rest of humanity, in spite of your tarnished face.

James Partridge, Changing Faces

Disfigurement has been steadily rising in the UK, with 390,000 cases reported in 1988 (Martin et al., 1988). Today, those figures have risen to over 1.3 million people with a mark, scar, or condition that affects their appearance, and, at present, over half a million people live with a facial disfigurement (Changing Faces, 2016). In 1988, the Office of Population Censuses and Surveys found that between 1% and 10% of the adult population claimed to have a deformity of some kind that severely hindered them from leading a normal life. This has highly increased according to Changing Faces' most recent report in 2017.

It is clear that disfigurement affects a considerable proportion of society, yet there is little in-depth research investigating the psychological difficulties of individuals who have accidentally acquired a facial disfigurement during adulthood (De Sousa, 2008) and how this may impact their identity (Martindale, 2014). Thus, it seems imperative to develop additional research in this area.

Note on Language

While working at Changing Faces, I quickly learned that it was inappropriate to use terms such as 'disfigurement' due to their negative associations, as they are considered devaluing and highly stigmatising (Yaron et al., 2017). Slateman and Yarom (2014, p. 244) confirmed this viewpoint regarding language, stating:

> Taking into account the privative meaning of the prefix dis, disfigurement literally means that one's "figure" or "form" has fallen apart, that it has become formless. Hence its exclusively negative connotations: defacement, deformity, blemish, deficiency, defect—the negation of bodily wholeness and beauty.

Hence, the founder of Changing Faces, James Patridge (1999), suggested using the term 'visible difference' or the correct medical terms, such as cleft lip or Bell's palsy, because they carry fewer negative connotations. Many key writers (Rumsey & Harcourt, 2004) have followed this, although the word 'disfigurement' is still widely used in literature and by charities such as Changing Faces and the Centre for Appearance Research. Throughout this research, I will use 'visible difference', 'altered appearance', and 'disfigurement' interchangeably, but I will only use the latter term as a noun (e.g. 'She has a disfigurement') rather than as an adjective (e.g. 'She is disfigured').

Developing My Research Question

My interest in conducting this research was originally sparked by Changing Faces, which supports individuals with any form of visible difference in the UK. However, my interest in disfigurement started at a young age because my grandmother made herbal medicine in Kenya for conditions such as acne, rosacea, and eczema. Many adults and

children would visit her for treatment, so I was exposed to a range of mild-to-severe facial differences, which influenced my curiosity of this unique topic. When I visited Kenya, I saw how marginalised this group has become in society and thought about how they are treated here in the UK. I assumed that having a facial disfigurement in the UK would be a different type of experience, although I later learned that this was not the case. While I worked for Changing Faces, they offered me a platform to further my interests through research, which later led me to my research question.

The investigations I conducted at Changing Faces were extremely thought-provoking and had surprising results. Along with the staff, many service users were passionate about the cause, inspiring me to research the area of disfigurement more intensely. On many occasions, I was given the opportunity to conduct research of my choice. One particular study that heavily stood out for me was a survey I conducted that asked participants about their experiences when accessing counselling. Questions from this inquiry examined issues such as how long it took for them to access psychological support and whether they had to ask for psychological support or were offered it. After advertising this survey on Changing Faces' social media, I received an astonishing number of responses with surprising results. The results showed that no participants had answered 'counselling' when asked what support and treatment they had received for their condition. Many commented that GPs and hospitals were only concerned with offering surgery or medication to 'fix' their visible difference so that they could look as 'normal' as possible. Participants were also asked who they talked to for emotional support: 38% replied 'no one', 47% said they spoke to a family member or friend, 10% talked to a staff member at their GP, and 5% gained emotional support through online forums.

Coming from a counselling background, I was also surprised at how little psycho-social support was offered to parents with infants who had a facial disfigurement, whether the children were born with it or had accidentally acquired it later on. I recall sitting in a meeting with Partridge, who also served as the head of research, in which he shared findings from a recent study that found that psychologists were placed in every dermatology unit that dealt with severe burns and skin grafts. However, no assistance was available for those who had a disfigurement, aside from medical attention and six sessions with an IAPT service after a long wait. Overall, it can be inferred that disfigurement has a considerable psychological impact on an individual, but De Sousa (2008) suggested that there is a deficit in current research regarding the specific psychological effects of facial disfigurement on those who acquire the disfigurement during adulthood. To date, there is also a dearth of in-depth studies within counselling psychology on the experiences of individuals with a facial disfigurement, especially in relation to acquired disfigurements and difficulties with one's identity. As such, the present study attempts to address this research gap by interviewing individuals who suffer with an accidentally acquired facial disfigurement and examining how they have subsequently constructed their identities.

I observed a similarity as to how individuals with an altered appearance were treated in both Africa and the UK. Although my grandmother sympathised with her patients and treated them with the utmost kindness, she also wanted to 'fix' them, which was comparable to what I found in my research at Changing Faces. The NHS simply wants to eliminate the disfigurement without providing psychological support for those coping with the physical differences or seeing how they feel after the tragic experience of losing their former appearance. This left me curious as to what the individuals themselves feel, as this is lost in the healing process.

My Position as a Researcher

When conducting the IPA for this research, it was important for me to be aware of my position as a researcher and how I view disfigurement. I believe I am an 'outsider' to this research and my participants, as I do not have a facial disfigurement and my identity has not been heavily affected by any outward change in my appearance. Having worked at Changing Faces and having met many individuals who had a visible difference in my childhood, I feel it is better to be an outsider with an empathetic understanding of disfigurement for this topic rather than an insider who is possibly too involved in the research, which could hinder seeing other participants' pain and difficulties should they differ from my own.

As an obvious outsider in relation to my participants, it was critical to consider that this would impact how I see and engage with them. More importantly, would this dynamic affect how they viewed me as a researcher, and would they engage differently with me because of the way I look?

To ensure I got the most out of my interviews and honoured the participants' authentic feelings regarding how they perceived their identities, I used my training as a counselling psychologist to give each participant a voice and to avoid allowing my own views or research biases overshadow their experiences.

Adopting a Phenomenological Approach to Disfigurement

Phenomenology can be understood as the subjective way in which human beings gain knowledge and understand certain phenomena within the context of our own world. This approach can be seen as a way of unravelling the dimensions of individual human experiences and how we exist and live in our world. Therefore, a phenomenological approach allows us to gain access to an individual's experience with accidentally acquiring a facial disfigurement and how they experience their identity through entering into an intimate dialogue to help understand their point of view. There are many other approaches that could have been used to research this topic, yet none sufficiently valued the sensitive experiences of my participants. For example, a scientific approach could have been used, similar to the previous research I conducted at Changing Faces. However, although those investigations gave me valuable results and shocking findings, the scientific approach lacked depth and failed to capture the real, lived experiences of each participant.

Using a phenomenological approach to studying disfigurement will focus on how individuals with a disfigurement experience their bodies (Slatman & Yaron, 2014). Everything we experience is subjective, directly from our internal perceptual lenses. Hence, it is impossible to leap out of ourselves and experience our external world. Therefore, phenomenology suggests using what is available: our thoughts, beliefs, experiences, and perceptions (Carel, 2018).

To summarise, Carel (2018 p.127) stated:

> On the phenomenological account, illness is no longer seen merely as biological dysfunction to be corrected by medical experts. Because of phenomenology's focus

> on the subjective experience of the ill person, it sees illness as a way of living and experiencing the world and interacting with other people. Instead of viewing illness as a local disruption of a particular function, phenomenology turns to the lived experience of this dysfunction.

Facial disfigurement is not necessarily an illness or a biological dysfunction, although it is treated the same way by medical professionals to some degree. This outlines the importance of using a phenomenological approach while researching accidentally acquired facial disfigurements.

Counselling Psychology and Facial Disfigurement

James (2013) stated that unlike the medical model, which largely focuses on categorisation, diagnosis, and pathology, counselling psychology has a more non-pathological and relational stance towards individuals with a visible difference. Most research in this field is centred on the subjective experience of cancer patients, who have acquired a disfigurement as the result of cancer treatment (Baker, 1992; Callahan, 2004; Rumsey, 2004; Turpin et al, 2009). Although health and social psychologists are interested in facial disfigurement, there is a lack of literature within the field of counselling psychology, which is shown in the following chapter. This shortage may be because counselling psychology is a relatively recent discipline. While the specialisation developed rapidly in the UK between 1982 and 1994, the British Psychological Society did not officially recognise it until 1994 (Starwbridge & Woolfe, 2010). Overall, the topic of facial disfigurement has significant relevance to the field of counselling psychology because of the adverse consequences that can impact an individual's sense of self, including trauma, distress, and negative emotions. As such, the findings from this research aim to contribute to

the knowledge by offering in-depth insight in order to aid practitioners treating individuals who have psychological problems associated with their self-image.

By developing an understanding in this field, counselling psychology practices can be made more appropriate to treat individuals with facial differences and any psychological difficulties that may come with it. Thus, this study seeks to support practitioners' understanding when working with individuals who present with a sudden, accidentally acquired facial disfigurement. This study also anticipates offering unique insight regarding six female participants who have an accidentally acquired disfigurement and their in-depth views of how this experience may have had a specific impact on their identity. This should help support practitioners by increasing their knowledge and helping them design suitable intervention treatments for this type of experience.

Literature Review

Overview of Chapter

This chapter will provide an overview of the relevant literature on identity and its links to the face. It will uncover relevant literature on the phenomenology of identity, facial disfigurement and, more specifically, how our understanding of identity can be used to understand the process of accidentally acquiring a facial disfigurement. Overall, most of the research included in this literature review will be qualitative rather than quantitative, as this research aims to adopt a phenomenological approach. Along with this, I will mainly focus on relevant prior research within the discipline of counselling psychology. However, because research on visual difference is scarce within this field, I will touch on other fields, including philosophy, health and social psychology. Finally, this chapter will end with a justification for the current study and its significance, along with clearly established aims and objectives for this research.

The Phenomenology of Identity

As the basis of this research is focused on 'identity', specifically in terms of its relation to the face, it is important to identify the link between them. The concept of identity has many layers grounded within phenomenology that aid us in understanding the more complex underpinnings of individual identity. In order to do this, it is necessary to explore the origins of identity and to try to establish its links to the face. Merleau-Ponty (1962) was one of the first philosophers to establish the phenomenology of identity and how we perceive our world. He went on to develop the lived-body account of personal identity, which

highlighted the idea that one's personal identity does not consist of the mind alone. He argued that we are living bodies or embodied selves, and thus a conscious being is a combination of mind and body. This means that in the lived-body experience, the body is not simply experienced as an object; instead the experience is more complex and divided into a combination of components, such as rational thought or physical pain (Crossley, 2001). Hence, he believed that we are embodied selves incorporating conscious and unconscious mind and body components existing within a specific time and place (Toombs, 1993).

Husserl's phenomenology also addressed the importance of this factor when considering identity, as he explored what it means to experience oneself as a continuous being (Carel, 2011). He addressed the concept of experiencing oneself as the same person at different times and in different places. This refers to the combination of the body's sensory-motor functioning along with the intimate experience of 'oneness' with one's body, such as the feeling of being present in the here and now and feeling immersed in the body (Merleau-Ponty, 1962; Leder, 1990). The merging of the mind and body in this way is what Merleau-Ponty named 'embodiment', which encompasses a meaningful engagement with one's 'lifeworld'.

This lifeworld can be understood as a collage of all our experiences; it includes the summation of every lived day and all of our past, capturing everything we take from our world that becomes meaningful. Therefore, our lifeworld is the lived experience in each relationship or situation that unfolds within our everyday lives (Van Manen, 1997).

It can be argued that many things that alter our lifeworld or everyday lives can therefore also have an impact on our identity. For example, experiences such as illness can

disrupt an individual's structures of daily life (Bury, 1982). Therefore, when illness or something physical occurs, 'it not only disrupts the body but also the relationships and networks of the person involved' (Martindale, 2014, p. 16).

In addition, many scholars argue that the body acts as a representation of the self. Firstly, the face differs from other body parts because it is almost always visible to others, along with its uniqueness, which makes us recognisable to ourselves and others (Martindale, 2014). Merleau-Ponty's theory (1962) supported the significance of the face alone, as he argued that a well-established sense of self, linked with the centrality of the face in terms of its expression, are crucial to our social relationships. He went on to state that we exist in the facial expressions of others, as they do in ours, emphasising that the face and body (along with the mind) are central to identity and the self. Thus, signifying the purpose of studying identity in relation to the human face.

As the 'self' and 'identity' are crucial concepts explored within this research it is important to establish the meanings and differences between them. When referring to the 'self', this can be described as organised conformations of one's perception of who one is. Ones self-concept can be described as an "overall vision (as an integrated, coherent, and stable individuality) transcending the experiential and event content of self-awareness" (Lipiansky, 2008, p. 38). 'Identity' however cannot simply be reduced to one's cognitive structure yet encompasses a way of making sense of certain aspects of one's self-concept (Abrams, 1994).

Many different theoretical approaches acknowledge the numerous levels in which both the 'self' and 'identity' can be understood (Zacares, 2015). One way of understanding this process is through understanding these multiple levels, firstly personal identity refers to

one's beliefs, values and goals. Relational identity refers to one's identity that is present in everyday interactions with others, for example, one can be a friend, college, daughter or relative). Collective identity signifies ones belonging to specific groups such as ethnicity, gender or nationality. Along with these three core identity types, two psychosocial levels are equally as important. These are known as the ego identity which is associated to one's personality, unconscious processes, emotions, impressions and memories. Cultural identity is the second psychosocial level of identity, it is closely related to collective identity as it refers to one's cultural practices and one's emotional identification with the culture to which one belongs. Due to these multiple levels of both the 'self' and 'identity' this research will refer to 'self' as ones sense of 'who am I?', whereas 'identity' will encompass ones social presence, how one perceives and how others perceive them, as suggested by Hammell, 2006. This research will more specifically look at one's identity in relation to the external face, how one perceives their face and how their facial disfigurement is perceived by others.

Considering the Face and Identity

For centuries, many researchers have written about the relationship between the face and identity. Aristotle wrote about 'physiognomy', known as the practice of using outward appearances, mainly the face, to assess someone's personality and character. The earliest preserved document dedicated to physiognomy is 'Physiognomica', a treatise accredited to Aristotle. In this the author described using 'the characteristic facial expressions which are observed to accompany different conditions of mind, such as anger, fear, erotic excitement, and all other passions' (p.203) to create physiognomy readings (Todorov, 2017). The concept that personality lies within the external parameters of the face began to increase the importance of the face when considering identity.

However, James Parsons (1746) disagreed with this to some extent. He argued that it is not the chin or nose that allow us to determine a state of mind but rather 'it is the alteration of the muscles alone that is capable of demonstrating reigning passion of the mind upon every kind of face' (Todorov, 2017; p. 204). Although Parsons rejected the idea that we can determine someone's personality from the size of their facial features or expressions, he acknowledged the importance of reading emotional expression through the muscles in the face in order to assess inner feelings.

In support of this, the phenomenological significance of the face is linked to others' perceptions of us. They will use the uniqueness of our face to differentiate us from others, and to perceive and interpret our appearance and identity (Perpich, 2010). Levinas also 'recognised that face incorporated notions of facade, personhood, agency, interaction and cognisance' (Martindale, 2014; p. 61). It can be argued that these can also be understood as appearance, identification and communication, rather than just 'corporeal coverings' (Martindale, 2014; p.61). Overall, these early philosophies acknowledged that the face offers much of our recognisability for others, as we all carry unique faces and rely heavily on the ability to recognise one other visually. This places the face at the forefront of our identity.

From an embodied perspective, we access the outside world through our senses. These include tasting, smelling, seeing and hearing, using organs that are all physically located within the facial region (Martindale, 2014). Therefore, Martindale claimed that 'to understand embodiment comprehensively, it is necessary to consider the complexities of facial sensory perception and expression' (p.70). In addition, every part of the human face aids us in accessing and experiencing the world. For example, the eyes allow us to communicate with and interpret others' meaning. Eye contact is also used in interactions (Synnott, 1993) to identify objects and people and to express emotions, as we wink and cry

using our eyes (Martindale, 2014). Our ears, mouth and nose are also used to communicate with and perceive the world around us. In addition, Rudge (2009) believed that our skin can be hugely overlooked as a critical physical entity that is used to investigate the world. It can be argued that the skin 'acts as a visible and palpable boundary, between the inner and outer worlds of the embodied self' (p.72). Hence, these critical markers located in the face provide reasons for analysing the face to explore identity.

Although this link between identity and the face has been noted for many years, to my surprise little attention has been paid to the underlying impact on identity when the face is suddenly altered in any way. While researching this topic I struggled to gather existing literature from the field of counselling psychology; I was steered towards health psychology, biology and philosophy studies, mostly those researching facial transplant surgery. Some research on facial transplantation has suggested that identity is directly linked to the face (Carolessa & Pradeu, 2006; Swindell, 2007; Modgil, 2011). As suggested above, if identity can be visually represented or indicated within the human face through expression, what happens when the structure of the face is made unrecognisable or redefined in any way? Is the individual's identity reduced or changed? If so, could it be argued that identity is somewhat replaced and restored after facial transplant surgery?

In an attempt to find the answers to these questions, I turned to qualitative data on facial transplant surgery to find out how people who had received this experienced their identity. Some talked of: 'The horror of being faceless, of forgetting one's own appearance, of having no face. The face is the mirror image of the self' (Hull, 1990; entry for 11th January 1984). Others who underwent a facial transplant operation felt that it symbolised being reborn. In addition, they argued that it was not only a matter of transplanting a new

face, but also meant transplanting the foundations of identity (Lafrance, 2010; Le Breton, 2015; Perpich, 2010). In support of this, a recent review of literature by Nazzi et al. (2017) on the psychological outcomes in face transplant recipients found that: 'Recipients were generally satisfied with the aesthetic result of the procedure, succeeded in integrating the new face into their sense of self within the first few weeks to months post-transplant, and experienced a major and lasting improvement in social integration for years after the transplant' (p. 9). Overall, this review found that both qualitative and quantitative research established mostly positive psychological outcomes in participants who underwent face transplantation. Some related qualitative results reported one participant who stated that he remembered his 'disfigured' face but, having gone through a face transplant, now feels he can accept his new face along with a new identity. As my research is based on participants who have not gone through this procedure of acquiring a completely new face, I believe my results will be contradictory to these, as participants for this research continue to live with an accidentally acquired facial disfigurement.

Although, this led me to wonder about the process of developing a new identity after acquiring someone else's face. Carolessa and Pradeu (2006) supported the argument that 'the transplantation of visible organs [such as a face] provokes more serious questions for the recipient. Visible organs are components of an individual's identity...' (p. 183). Swindell (2007) continued this conversation on facial transplant surgery and its links to identity, stating that participants go through 'the potential to feel that their identity is a mix between their own and the donor's' (p. 449). Following this, Swindell (2007) claimed that: '[in the case of] facial allograft transplantation, the person is gaining an identity, whereas in the case of severe facial disfigurement, the person is losing an identity' (p. 451). This implies that, by accidentally acquiring a facial disfigurement, participants will also experience a loss of

identity. Therefore, this indicates that the tergal parts of our identity are developed and changed in relation to major changes to our physical face.

This concept that the face is a unique marker of our identity is supported by research on how we perceive faces and identity in regard to the onset of blindness. Cole (1997) conducted a review into how blind individuals construct others' identities without the ability to see faces. Cole concluded that the face is not simply an expression of the self that is available for others to perceive, but more specifically 'the self is constituted in the face and developed, and experienced, in the interaction between faces' *(p, 482).* These findings support Merleau-Ponty's (1962) view that the face is a central part of our identity, as it conveys expression and communication with others. Therefore, this relates to the current research topic, as it supports the notion that the face can play a vital part in perceiving the identity of others and of ourselves.

More recently, Carty et al. (2012) supported Cole by researching blind recipients of facial transplant surgery. They found that blindness was a huge factor when participants were adjusting to their new faces, as they could not see the results of their lost and restored identities. This meant they had less confusion over who they were and how they viewed their identity, in comparison to those who experience an identity 'shift'. These studies help us see that identity is not disturbed when the face cannot be seen, even if it has been changed. Though participants struggled to determine the identity of others when they could not see their faces, blindness helped reduce the difficulties for individuals who could not see the differences in their new facial appearance. This highlights the importance of seeing the face, in order to help us perceive the components of identity of others and of ourselves. However,

these studies fail to establish the reasons why the face plays a crucial role in assessing identity.

Other scholars within the social sciences and humanities have sought to specifically explore the psychological impact of facial disfigurement on the concepts of 'self-image' and 'self-identity' (Fearon, 1999). Research using narrative analysis was conducted on illness-related acquired facial disfigurement, facial transplant surgery and identity; the findings suggested that a person's identity is located within the face (Martindale, 2014). For example, Glover (1989) stated that: 'we think of ourselves in terms of the face we are used to, so that a damaged face damages our sense of ourselves' (1989. p. 72). Although dated, this shows the importance of looking at identity via the face, especially for those who have suddenly lost the face they always had. McEachran (2016) also added that: 'if we couldn't identify our face, would we have an identity at all?' (2016, p. 39). These are very bold statements that highlight the importance of further research into the links between the face and identity.

As mentioned above, Martindale (2014) conducted a highly relevant study in the field of philosophy, *A Life Lived: Experiencing Facial 'Disfigurement' and Identity Shift.* This is the most relevant research known for the current study. Martindale aimed 'to examine socio cultural values associated with human faces in predominantly Western societies using secondary sources' (2014, p.24) and to 'explore the relationship between acquired facial "disfigurement" and embodied identity shift using a narrative methodology' (2014, p.24). The analysis from this research found that: 'faces are important. However, identities are not located within them but created and reshaped through embodied life experiences' (p.1). The findings also showed that: 'the relationship between embodied identity shift and acquired facial "disfigurement" is one of contested negotiation between wider socio-cultural facial

values, transitional/liminal identity states during and after the event(s) and the aim of previous identity restoration' (2014, p.1).

Jaspal (2012) also contributed to this discussion and conducted a study into the challenges to identity and the coping strategies of individuals with a facial disfigurement. This study implies that individuals who acquire a visible difference are highly prone to experience a threat to their identity. However, there is a lack of in-depth research into the relationship between faces and identities (Martindale, 2014). Thus, it can be argued that by providing a rich-textured description of lived experience for those who accidentally acquire a disfigurement, we can better understand the psychological impact on their identity.

Accidentally Acquired Facial Disfigurement and Identity

These studies on facial transplantation give us insight into what happens to identity when the face is restored. However, the present research is only concerned with what happens to identity when acquiring a facial disfigurement, rather than when receiving a whole new face. Therefore, it is important to focus on accidentally acquired disfigurement rather than congenital disfigurement. It can be argued that individuals who are born with a disfigurement go through a different psychological process from those who acquire a difference at a later stage (Rumsey & Harcourt, 2004). Individuals with a congenital disfigurement are more likely to incorporate their visual difference as part of the self and adapt to living in this way. In contrast, those who have an altered appearance later in life are more likely to face a loss of sense of self and identity (Martindale, 2014), because the way they once were has unexpectedly changed. They are faced with re-considering who they are along with having to adjust to the stigma of looking different (Versnel, Duivenvoorden, Passchier & Mathijssen, 2010). Therefore, one's 'previously known lifeworlds and embodied

identities become disrupted and threatened' (Martindale, 2014; p.27). Thus, this particular group is more relevant to this research into identity and the face, as it can facilitate in-depth exploration into how identity is experienced when the face is altered.

Having to adjust to life with a facial disfigurement after spending decades without one, presents a range of diverse psychological challenges, which can have a transformative and significant impact on the perceptions of self (Dropkin, 1989; Rumsey & Harcourt, 2004). Jones et al. (2017) conducted a qualitative study on the experiences of older adults living with appearance-altering burn injuries. Their findings showed that participants struggled to let go of the way they once looked and to accept their altered appearance. The hardest part was integrating their accidentally acquired disfigurement into their identity. This study concluded by stating that huge psychological difficulties need to be confronted when one accidentally acquires a facial disfigurement and emphasised the importance of further research within disfigurement to enable counselling psychologists to 'tailor psychological support and appropriate interventions' (p. 25).

On the other hand, Callahan (2004) studied participants who acquired a facial disfigurement as a result of head and neck cancer. This study uncovered a huge sense of loss as participants experienced a threat to themselves; they were no longer the person they were familiar with and knew themselves to be. In support of Callahan, Murray and Rhodes (2005) conducted a study named *Nobody Likes Damaged Goods*, where they used IPA to understand the internal realities of participants who suffered from acne. They found four superordinate themes: powerlessness, comparisons, self-image and identity.

Their findings showed that participants experienced huge psychological difficulties, including reduced self-confidence, self-esteem and self-worth, frustration, depression and even suicidal thoughts. One of the key findings taken from this research is the idea of a 'fluid identity', which researchers described as: 'the process in which an interviewee's outlook and behaviour became a product of how visible and unappealing they experienced their acne to be, and where both their identity and skin condition were in a constant state of flux' (p. 15). Overall, participants viewed their acne as a separate entity, yet it was also in some regards part of them as if *'*woven into a sense of identity, continually revising and moulding the expression of self*'* (p. 15). Therefore, these studies demonstrate that there are many challenges to identity when a facial disfigurement is accidentally acquired, emphasising the need for more in-depth exploration into the unique process of coping with potential struggles with identity.

In contrast, Modgil (2011) researched identity and its links to facial transplantation. His conclusion was as follows: 'my findings suggest that donor facial allograft may be identified on the recipient's face depending upon underlying craniofacial morphology and accordingly, identity changes can be suitably predicted' (2011, p. 171). To summarise, Modgil found a way to objectively quantify and predict the extent of a person's identity shift after facial transplantation by employing a scientific model that involved using 'underlying craniofacial morphology' (p.171) and taking a number of facial measurements. Through the use of positivist methodology, Modgil supported the Cartesian theory that the mind and body are separate entities and not related to one another.

This quantitative study has relevance to facial disfigurement and identity. However, it lacks validity and narrowly views identity as being directly located and measured in the

human face. Philosophers such as Merleau-Ponty (1962) would disagree with its findings, as they believed that the concept of identity is much more complex and cannot be scientifically calculated. Furthermore, Martindale (2014) disputed the use of positivist methodology and Cartesian dualist ideas, which see the mind and body as two separate entities, in order to research 'the relationship between acquired facial "disfigurement" and embodied identity disruption' (p. 179).

Considering my epistemological stance and the phenomenological research approach, identity will not be discussed as purely anatomical and directly linked to the face alone. Instead, the topic of identity is a much more complex phenomenon that is composed of many attributes and complexities, which cannot be understood from one epistemological position or discipline. The distinction between these two studies is that one uses a scientific method and the other uses narrative analysis to achieve a more in-depth view of participants' experiences of identity after acquiring a facial disfigurement. This leaves a gap in research for in-depth phenomenological understanding of the experience of accidentally acquired facial disfigurement and the experience of identity. As Finlay (2006) argues, across phenomenological studies the body is 'strangely absent' (p. 20).

The Lived Experiences of Accidentally Acquired Facial Disfigurement

Rahzani et al. (2009) used grounded theory to analyse the social impact of living with an accidentally acquired facial difference, specifically in burn patients. This research was comprised of 21 participants, with each experiencing some degree of negative reaction whenever they tried to socialise with others. Some found that people gazed intently at them,

avoided them, asked intrusive questions and even mocked them because of their altered appearance.

Similarly, Bonnano and Esmaeli (2012) also used grounded theory to analyse the social impacts of acquiring a facial disfigurement in 12 cancer patients. This study specifically focused on the participants' interactions and reactions with and from others; they found that they felt a huge amount of intrusion, stigma, sympathy and neglect. These studies provide insights into the psychological difficulties people may face when trying to live with an accidentally acquired facial disfigurement. Though researching accidentally acquired facial disfigurement is useful from a grounded theory point of view and can add value to our knowledge of the social processes that people with a visual difference encounter, it neglects the in-depth experiences of identity when one's face changes and lacks 'ecological validity' (Willig, 2008).

A highly relevant study was conducted by Threader and McCormack (2015), who introduced the concept of identity change through an in-depth exploration of participants who had gone through the unfortunate experience of head and neck cancer. The study aimed to examine the trauma, stigmatisation and growth of nine participants who had experienced head and neck cancer specifically. The researchers used IPA to analyse their results. This study generated four key superordinate themes, the most relevant to this research being 'THIS cancer: stigma and distress'. The sub theme that created this superordinate theme was 'identity struggle'. As the participants had gone through a surgery that altered their appearance, they had great difficulty in adjusting to a new 'self', an experience that was named 'identity struggle'. The study found that this process was significantly traumatic for these individuals, as they failed to identify with their old 'self'.

Due to the change in appearance, participants had also become more withdrawn from society and their personalities had changed, leaving them confused about who they were and how they experienced their identities. The research also produced some relevant findings for the present study, as participants eventually defined a new 'self' and discovered a sense of belonging with others who had overcome a similar experience of acquiring a disfigurement. Overall, this research is useful in understanding the difficulties that individuals who have accidentally acquired a facial disfigurement may struggle with, such as their identity and the potential of a shift in identity.

Similarly, Turpin et al. (2009) published a qualitative study on meaning-making for ten head and neck cancer patients. This IPA study generated several interesting results, which were mostly related to how gaining a facial disfigurement can impact the 'self', when it was necessary to acquire it in order to survive. The four themes gathered and shared in these results were *'*destruction of self'*, '*altered relations with the body'*, '*disenfranchised self' and *'*conservation of self'. The first superordinate theme, *'*destruction of self', explored participants' 'fundamental sense of self' (Turpin et al., 2009, p. 31), which had a substantial impact on males, because becoming unemployed meant that they were left feeling useless. These feelings affected how they saw themselves and their identities. Overall, this theme showed that all participants struggled with the loss of the 'self' and their former physical appearance. They also felt they had lost crucial roles that they had once fulfilled within their relationships.

The second theme, 'altered relationship with the body', related to how participants talked about their bodies. Acquiring a facial disfigurement added negative connotations to

their self-perception. Many saw themselves as ‘ugly’ or ‘not normal’, and their talk became extremely self-critical. ‘Disenfranchised self’ dealt with the participants’ experiences with others and feeling scrutinised and exposed because of their facial difference. This theme revealed the crucial point that others’ reactions to them made them feel as though they had been trapped in a body that was not a real representation of who they were, showing a disconnect between their sense of self and their physical exterior.

Finally, the fourth theme, ‘conservation of self’, looked into ways that participants tried to view themselves positively, and many saw themselves as survivors when they had previously felt like victims. Turpin et al. (2009) has argued that the new ways in which participants constructed their sense of self was a ‘pragmatic’ sense of acceptance and not a real or complete acceptance of who they were after the altered appearance. This was because the researchers felt the participants were experiencing a state of ‘emotional and cognitive avoidance’ (Turpin et al., 2009, p. 38).

Overall, this study was very useful when examining the sense of self for ten men and women who had accidentally acquired a facial disfigurement as the result of surgery related to head and neck cancer. Although this research is somewhat similar to the current proposed study, it incorporates a sample of individuals who had been diagnosed with a specific type of cancer and then had surgery as treatment, which left them with a visual difference. It can be argued that this puts these participants in a different state of mind, as their disfigurement was a compromise for survival and was not ‘accidentally acquired’. Acquiring a facial disfigurement to stay alive compared to the result of an unexpected accident can lead to differing experiences of identity, as cancer has severe and ongoing consequences to health. In this instance, a disfigurement was caused deliberately in an attempt to save the participant’s

life. However, accidentally acquiring a facial disfigurement as a result of a house fire or car accident tends to be sudden and not the result of treatment, though in both instances participants come close to death and survive with a disfigurement. In contrast, the participants used in this study were selected on the basis of having accidentally acquired their disfigurement in an incident such as a car, motorbike or jet ski accident. Furthermore, the present research used only female participants, making the sample more homogeneous.

Similarly, Roing, Hirsch and Holmstrom (2007) also conducted a qualitative study utilising the hermeneutic approach on cancer-related disfigurement. Their themes included 'existing in the eyes of others' and 'existing with others'. These themes explored the participants' difficulties in living in society with their cancer and the visible differences in their appearance as a result. They mostly expressed fear of how they would ever 'exist in the eyes of others*'* while looking the way they now did. Although this research is highly relevant with its methodological approach and analysis, it focuses more on participants' illness rather than the visual difference they acquired as a result of their oral cancer diagnosis. Therefore, it is difficult to know whether these participants struggled with reactions, such as pity and compassion, due to their disfigurement or their newly found cancer diagnosis. Furthermore, they may also be seen differently by others, due to the sensitive and life-threatening nature of cancer.

This research also used a sample of both men and women. It is unclear whether gender correlates to greater amounts of disfigurement-related cases or psychological impacts. However, females evidently dominate the studies on facial disfigurement (Hill & Kennedy, 2002; Moss & Carr, 2004; Gardiner et al., 2010). This discrepancy could occur for many reasons, but one of the main factors is that women are more likely than men to seek treatment

for visible differences and are, moreover, more likely to be concerned about their scars, making them more likely to take part in research (Hiatt et al., 2009; Thombs et al., 2008).

Gaps in Research Literature

Overall, although 'disfigurement' has been researched across a number of different fields, most of the studies on disfigurement take place in social and health psychology, where the main focus is on beauty and appearance (Rumsey & Harcourt, 2005). Cancer-related disfigurement is also widely researched, with studies mainly using quantitative methods (Dropkin et al., 1983) and some recent studies utilising qualitative methodologies (Threader & McCormack, 2015). More recently, the relationship between identity and acquired facial disfigurement has been researched from the perspectives of biology (Modgil, 2011) and philosophy (Martindale, 2014). While acquired facial disfigurement has been researched in the psychology field, very few studies consider the experience of identity (Turpin et al., 2009). It is yet to be researched within the counselling psychology field.

Researching this current topic from a counselling psychology viewpoint offers professionals an insight into this unique experience. With more knowledge on the experience of identity when accidentally acquiring a facial disfigurement, clinicians are better placed to support these individuals and any challenges they may experience with their identity. This also highlights the importance of psychological support along with medical assistance and the value of working on identity throughout treatment, rather than simply managing others' intrusive reactions or adjusting to the new face alone. It is important to focus on what the incident has meant for the person's identity and who they are as a person. In conclusion, there is a lack of in-depth research regarding the experiences, perceptions and perspectives of identity after acquiring a facial disfigurement.

Present Research

The previous section highlighted the current gap in the existing literature about the effects of acquiring a facial disfigurement and the associated impacts on an individual's sense of identity. Researchers believe that addressing this gap could enable us to understand how accidentally acquiring a facial disfigurement can impact a person's perceptions of his or her identity.

This research seeks to address the question, 'How does accidentally acquiring a facial disfigurement affect the perceptions, perspectives and experiences of identity for individuals?'

Methodology

Overview

This chapter will explore the chosen methodological approach and explain its ontological roots and the epistemology used to analyse and answer the research question: 'How does accidentally acquiring a facial disfigurement affect the perceptions, perspectives, and experiences of identity for individuals?' I will also address the method used to recruit participants and collect interview data. Lastly, this chapter will outline the analytic steps employed to analyse the data in Chapter Four.

Qualitative Paradigm

Though I previously conducted many quantitative research studies on disfigurement at Changing Faces and throughout my academic journey, I felt that they did not capture the essence of the individuals' rich experiences or the experience of living with a facial disfigurement. As shown in my literature review chapter, identity is an extremely complex phenomenon that cannot be explored in-depth through quantitative methods. As Morrow (2007) suggested, qualitative research is the most useful way of understanding the meaning participants take from their individual experiences. Therefore, this study clearly suits a qualitative paradigm, as it hopes to provide an in-depth exploration of the lived experiences of this carefully selected, homogenous sample.

Rationale for Adopting a Qualitative Paradigm

Morrow (2007) argued that a study's research question should be the primary focus and determine the choice of design used. Research questions that explore 'how' certain individuals cope with a specific difference or 'what' it is like for them to live with a particular condition are common themes in qualitative research questions. Qualitative research questions are mostly concerned with how participants make sense of their world and experiences (Willig, 2008) and the 'experiential life of people' (Polkinghorne, 2005, p. 138). Likewise, this research aims to understand 'how' accidentally acquiring a facial disfigurement may affect individuals' perceptions, perspectives, and experiences of identity. Moreover, Morrow (2007) stated that qualitative approaches can be used to further explore experiences that are not easily identifiable, such as identity.

In contrast, quantitative research is concerned with acquiring knowledge by formulating hypotheses and then systematically exploring them with the intention of finding cause-and-effect relationships (Willig, 2008; Gravetter & Forzano, 2006). As explored in the literature review, identity is a broad, unseen concept that incorporates many layers grounded within phenomenology that cannot be accurately measured through quantitative methodologies Therefore, it could be argued that applying a quantitative approach is not appropriate for researching in-depth perspectives, as this approach is objective and mostly concerned with a fixed, measurable reality.

Epistemological Stance

Baron (2002) defined epistemology as how we know what we know. As Willig (2012) proposed, the process of understanding and being aware of one's own epistemological perspective is central to any research. He established three broad epistemological positions: phenomenological, social constructionist, and realist. Each reflects on a different approach as to how we gain knowledge, along with contrasting ways of collecting data and performing analyses.

As a researcher, I position myself within the critical-realist epistemology, which combines both the interpretative and realist perspectives. Unlike scientific realism, which argues that scientific methods are the best mode of enquiry to uncover true representations of our world, critical realism argues that 'the way we perceive facts, particularly in the social realm, depends partly upon our beliefs and expectations' (Bunge, 1993, p. 231). Therefore, critical realism accepts an implicit subjectivity in the production of knowledge and has some commonalities with constructionist positions (Watkins, 1994-95). The 'critical realism' (Willig, 2012) definition acknowledges that 'facial disfigurement' is a real concept and that experiences related to visual differences exist in the real world, while also recognising and critiquing how reported meanings associated with these phenomena are mediated by the socio-cultural context in which they originate (Lawthorm & Tindall, 2011).

This epistemological position seems to fit this research best, since it acknowledges that we interact with the world and one another grounded in our own contexts. Hence, we have unique expectations and beliefs. A critical realist position acknowledges that there are

fundamental truths in our world, such as accidentally acquiring a facial disfigurement, but such an event will be understood and experienced differently by each participant due to individual subjectivity.

Although IPA does not claim a specific epistemological position (Larkin, Watts & Clifton, 2006), Bhaskar (1978) argued that it is theoretically rooted in critical realism and the social cognition paradigm (Fiske & Taylor, 1991). To support this idea, Madill et al. (2000, p. 3) stated that 'critical realism admits an inherent subjectivity in the production of knowledge', which is in line with the theoretical underpinnings of IPA (Smith, 1996).

Interpretative Phenomenological Analysis

Compatibility of Interpretative Phenomenological Analysis and Counselling Psychology

Qualitative methods seem to be the most suited to the principles of counselling psychology (Hoyt & Bhati, 2007). Similar to the way we work with clients, IPA enables researchers to explore in-depth stories, thoughts, feelings, and participants' sense of identity (Smith et al., 2009). Therefore, I have adopted this phenomenological approach due to its nature of exploring participants' in-depth experiences of a specific phenomenon.

Hermeneutics emphasises the interpretation and meaning participants' attach to this phenomenon, along with idiography that concentrates on the unique experience of each individual as part of the context in which it occurs (Smith et al., 2009). In this study,

participants are attempting to make sense of their experience of identity after accidentally acquiring a facial disfigurement, which I will interpret in order to try to understand if and how identity is impacted throughout this unique experience. Smith (2004) stated that 'IPA also allows a hermeneutics of questioning, of critical engagement, as the reader may well ask questions and posit meaning which the participants would be unlikely, unable or even unwilling to see or acknowledge themselves'. In supporting the use of hermeneutics within counselling psychology research, it could be argued that this is what counselling psychologists are trained to do with clients. Hence, Morrow (2007) argued that counselling psychologists often find qualitative approaches more in tune with their therapeutic work.

It should also be noted that counselling psychology's subjective, reflexive, and inductive approach (Eatough & Smith, 2006) matches IPA's epistemology. Jeong and Othman (2016) stated that IPA uses a bottom-up approach to gather knowledge, and this viewpoint is shared by counselling psychology, as the field strives to produce information by being practice-based.

Consideration of Other Methodologies

The three research methods I considered as alternative options were narrative analysis, thematic analysis, and grounded theory.

Narrative analysis focuses on subjectivity and the lived experiences of individuals. Lyons and Coyle (2007) summarised narrative analysis as a way to analyse participants' thoughts and feelings and how they reflect on themselves and their experiences. Both IPA and narrative analysis share a similar epistemology because they have common

phenomenological roots (Bruner, 1990). However, the methodologies differ in that narrative analysis accepts the structure imposed on the story by the narrator and delves deeply into why it has been structured this way rather than into how people make sense of their unique stories (Riessman, 1993).

Similar to IPA, thematic analysis aims to examine themes and patterns across data. However, IPA focuses on developing each individual case before moving to the next, while thematic analysis involves developing each stage of the analysis across the data as a whole. Therefore, this method would not suit the sensitive data gathered in this study or value each participant's unique experience (Braun & Clarke, 2006) and different difficulties with identity and types of disfigurement. Thematic analysis would not capture this uniqueness as well as IPA.

Lastly, grounded theory was considered due to its emphasis on finding indicative theories within the data while also being suitable for studying individual or interpersonal processes and experiences (Charmaz, 2006). Although it would be an interesting analytic method to use, it focuses on social processes and constructing a theory about a topic rather than on understanding and interpreting a phenomenon (Willig, 2008). In other words, grounded theory would move the research focus to the social processes of individuals, which IPA somewhat neglects, rather than to what living with this altered appearance means for such people.

Rationale for IPA

Research questions chosen in an IPA framework focus on participants' unique experiences and understanding of a particular phenomenon, which is, in this case, how they have experienced accidentally acquiring a facial disfigurement. Smith and Osborn (2008, p. 53) supported this, as they asserted that 'detailed examination of the participants' lived experience is concerned with the individual personal account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself'. Overall, this phenomenological approach is suitable for this research due to its nature of exploring participants' consciousness, which is subjective to their experience of a specific phenomenon.

Having chosen IPA as the research methodology, its ontological (how things are) roots and the epistemological (how we conceptualise what can be known) stance it takes to gathering knowledge (Crotty, 1998) need to be explained. IPA allows these unique experiences to be respected and carefully analysed individually, so these factors support it as an appropriate analytical method for this study. This study aims to unpack the experiences and identities of the six participants, who have an accidentally acquired facial disfigurement, and keep them at the heart of the research.

Phenomenology

As this research has a phenomenological approach, it is important to discuss the roots of phenomenology, both generally and in the context of this study. One of the earliest writings on phenomenology appeared in the twentieth century by Edmund Husserl, who

founded the school of phenomenological philosophy. He was specifically interested in how we perceive the world and in the idea of being able to bracket off our assumptions, judgements, and perceptions to consider just the phenomena (Smith et al., 2009) from a 'phenomenological attitude' (Husserl, 1982).

Later, the phenomenological philosophers Heidegger (1962/1927) and Merleau-Ponty (1962) further developed Husserl's work. Initially, Heidegger (1962/1927) agreed with Husserl until he felt it was impossible to bracket off our natural attitudes and be reduced to just phenomena. Heidegger (1962/1927) regarded each individual as a 'being-in-the-world' and Merleau-Ponty believed in the importance of the subjective, body-as-it-is lived, or embodied.

Although these ideas differ, there are some similarities in how they have both contributed to IPA (Moran, 2000). Both are concerned with how individuals perceive certain experiences and the meanings they attach to these experiences in the context of their individual world. The notion of interpretations by participants regarding a meaning-making process is central to phenomenological research approaches such as IPA.

Overall, phenomenology can be defined by the philosophical study of lived experience. Aside from phenomenology, IPA also originated from other theoretical perspectives, including interpretation (hermeneutics) and idiography (Smith, 2004; Smith et al., 2009).

Hermeneutics

Interpretative phenomenological analysis is primarily understood through hermeneutics, which can be described as the study of interpretation (Smith et al., 2009). Hermeneutic philosophers such as Heidegger, Gadamer, and Ricoeur saw interpretation as a core element of our being in the world. Smith et al. (2009, p. 37) argued that 'without the phenomenology there would be nothing to interpret; without the hermeneutics the phenomenon would not be seen'. In the process of trying to phenomenologically understand another's world, participants try to comprehend the phenomena for themselves, which is the first interpretation. This is followed by a second interpretation from the researcher, who attempts to analyse and make sense of the data. This is known as double hermeneutics (Smith, 2004; Shinebourne, 2011).

Regarding this research, participants attempt to make sense of their identity after having accidentally acquired a facial disfigurement, and my interpretations of their understanding are analysed individually before the data are put together to create themes. This means that I am creating more than just a descriptive account of participant experiences. Rather, I am developing a richer, contextualised understanding of experiencing disfigurement as a phenomenon (Hein & Austin, 2001).

However, in order to successfully achieve this, I must continuously be reflective and remain aware of my own understandings and assumptions about facial disfigurement and my identity (Finlay & Gough, 2003). As suggested by Smith et al. (2009), to empathetically enter my participants' world, I must foster reflective practice rather than attempt to 'bracket off' my own assumptions and biases regarding facial disfigurement.

Smith and Osborn (2003) referred to this as ‘empathetic hermeneutics’ and also mentioned ‘questioning hermeneutics’, referring to when researchers consider how true the interpreted world really is. In order to get as close as possible to participants’ lived experiences, it has been argued that both empathetic and questioning hermeneutics should be combined (Smith & Osborn, 2003).

Idiography

Along with phenomenology and hermeneutics, IPA’s ideographic focus supports its value as a qualitative research method. IPA magnifies the experiences of a small few rather than attempting to extrapolate a more generalised understanding of a topic.

Procedure

In the following sections of the methodology, I will outline my procedure, recruitment strategy, data analysis process, and the ethical considerations relevant to this research.

Participants and Sampling

As IPA requires a homogeneous sample (Pietkiewicz & Smith, 2012), this study aimed to be as specific as possible and only include females who accidentally acquired a form of facial disfigurement between the ages of 18 and 65 (Willig, 2008). Use of a homogenous sample (Smith et al., 2009) allows researchers to understand and describe a particular group in-depth.

Due to the sensitive nature of this research and the possibility of re-traumatising participants, only individuals who I thoroughly screened using the questions in Appendix F and deemed fit to take part in the proposed research were interviewed. Once a participant got in contact and was willing to take part, I sent them an information sheet (see Appendix C). I gave them a chance to examine this document and arrange a call when they were available after they had been able to further investigate my research and what the interviews might involve. During this call, they either opted out of my study or wanted to take part, at which point I let them know that I had some questions before they signed an informed consent sheet and an interview was arranged. These questions are shown in Appendix F and include inquiries that sought to determine whether participation may have caused any acute or severe distress reactions.

Due to the specificity of my study, I opted for broad inclusion criteria yet remained mindful of ethical practices because of the sensitive nature of the phenomenon. In order to select a homogenous and ethically sound sample, I used the inclusion and exclusion criteria shown in the table below. I excluded participants that had ever been sectioned or were currently under any psychiatric care. This choice was made because many participants were being treated with mild antidepressants, but that did not mean they should be excluded from my study. I excluded severe psychiatric conditions, such as psychosis or schizophrenia, through my screening process, in which I collected the mental health history of each participant before my interviews. According to their mental health history, participants with severe conditions were excluded. During my screening process (see Appendix F) and throughout my interviews, I watched for any signs of acute or severe distress in order to stop the interview or participation if necessary.

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Female	Male
Accidentally acquired facial disfigurement between one and five years ago	Not aged 18-65 years
Near-native English ability	Not a UK resident
Thoroughly screened using Appendix (screening questions)	Born with facial disfigurement
	Currently in treatment for a severe psychiatric condition
	Anyone experiencing severe mental health problems and likely to become highly distressed
	Acquired disfigurement as the result of an attack

Figure 1. Inclusion/Exclusion Criteria for the Present Study.

Participants were gathered based on having accidentally acquired a facial disfigurement between one and five years prior to the interviews. This choice was due to this study aiming to examine how identity can be impacted by the onset of an accidentally acquired facial disfigurement. Therefore, including a timeline of between one and five years meant that participants may have felt more able to describe their experiences without the interviews causing re-traumatisation.

Recruitment

First, Changing Faces was asked to post an advertisement for my study (see Appendix A) asking participants to e-mail if they were interested in taking part on social media sites, including Facebook, Twitter, and Instagram (see Appendix B). The post initially stated the following: ‘Can you help? A researcher at Roehampton University is looking to interview women between 18-65 who have accidentally acquired a facial disfigurement in the last five years. If you'd be prepared to talk about this, please contact…’. The advertisement was later changed to read: ‘Can you help? A researcher at the University of Roehampton is looking to interview women between 18-65 who have survived an accident which may have changed their appearance in the last 5 years. If you'd be prepared to talk about this, contact…’. The alteration was because we wanted to be careful about the wording used in the posts (e.g. using ‘disfigurement’). We agreed that the new post was more appropriate for the audience and potential participants I wanted to find. This also led me to think more about the wording used throughout this research. As explained in the introduction, I wanted to move away from using the term ‘disfigurement’, as it has negative connotations, so I used other terms such as ‘visible difference’ or ‘altered appearance’. However, I also used ‘disfigurement’ because it is a common term used to identify the target group of this research. The justification for the use of social media as a recruitment tool for the study was due to the large audience that follows Changing Faces, which I had used in many previous studies conducted with this specific group.

Situating the Sample

All six women who took part in this study met the inclusion criteria and were selected based on my judgement after an initial screening call. This was primarily done via asking the participants some demographic questions (see Appendix E), such as name, age, location, year they accidentally acquired a facial disfigurement, and any difficulties since. Once participants had shown interest in taking part during this initial call, I asked some screening questions (see Appendix F) about their mental health history and any difficulties that they might have while taking part in this research or during the interview phase. My counselling psychology training and background aided me in deciding whether each participant was fit enough to participate and that the study would not cause any severe risks, including re-traumatisation. At this stage, participants were encouraged to ask any questions they had about the research and digitally sent an informed consent form to look over before the interview should they wish to continue participation.

Table 1. Participants' Demographic Details.

Pseudonym	**Age at Time of Interview**	**Accidentally Acquired Facial Disfigurement**	**Type of Accidentally Acquired Facial Disfigurement**
Anaya	36	Four years and three months ago	Car accident; suffered 90% burns; facial reconstruction surgery meant new cheekbones and jaw; many skin grafts over past 4 years.
Kiara	29	Three years and two months ago	House fire; suffered 70% burns over body; severe burn covering full neck up to mouth; 3 years of attempted skin grafts

Cienna	42	Three years and nine months ago	Cosmetic facial that used chemicals; face was eroded and left dark black, heavily affected where scalpel was used around whole face, except forehead.
Ellena	24	One year and six months ago	Car accident; skin above right eye completely re-grafted up to head injury; no eyebrows or ability to show expression in this area of face.
Maya	25	One year and six months ago	Motorbike accident; broken nose and three lost teeth; damage to face, leaving heavy scarring.
Tara	19	Four years and six months ago	Jet ski accident; facial scarring and palsy across the right side of face.

Data Collection

Semi-structured Interviews

This study used semi-structured interviews, as suggested by Reid, Flowers, and Larkin (2005). This style of interviewing encourages the creation of in-depth data and allows a more sensitive approach to put the participants at ease and make them feel comfortable during the interview. Since the topic was personal to the interviewees, it was critical that the questions were asked in an appropriate manner to allow the interviewees to answer in as much detail as they wished. As the researcher, I needed to build rapport and gain the participants' trust through an initial warm-up discussion to make them feel secure in the environment and ensure they were comfortable discussing more sensitive issues (Pietkiewicz & Smith, 2012). During the interviews, the participants were asked questions about their

accidentally acquired facial disfigurement and how the experience had impacted their identity. The questions were written in advance. However, the inquiries were not used as a strict guide, as more questions could have been asked on a specific topic to gain greater depth and understanding of an interviewee's answer.

Based on the literature review, the following types of questions were asked (see Appendix H for interview schedule):

- Would you feel comfortable telling me your story? How did you experience acquiring a facial disfigurement (Pietkiewicz & Smith, 2012)?
- What was going on in your mind then (Pietkiewicz & Smith, 2012)?
- Do you feel any profound difference to your self-concept or identity since the accident? If so, what is this difference (McGrouther, 1997; Rumsey & Harcourt, 2008; Pruzinsky, 1992)?

All interviews were recorded, and the participants were made aware of this fact prior to signing the consent form (see Appendix D) to take part in this research. The recordings were stored in a secure, password-protected location for transcription and analysis.

The interviews lasted approximately 60 minutes. The participants were given time to discuss how they found the experience and how they felt once the interview was completed. This step took place during a debriefing in which all practicalities of the research were addressed, including asking participants if they wanted a copy of the transcripts and a summary of the analysis (Appendix I). This led to the end of the interview after having safely provided the participants with space to reflect and ensuring they had all the relevant

information should they wish to withdraw from the study.

The interviews were audio-recorded and later transcribed for analysis. Depending on where was most convenient for the participants, the interviews took place at Changing Faces' offices or alternative confidential settings, such as the University of Roehampton. For my safety, I let someone know when and where I was conducting each interview.

Conducting the Interviews

As I met each participant in the Changing Faces waiting room, I offered them some water and escorted them to the interview room we would be in that day. As we sat down, I showed them all the fire exits as requested by Changing Faces, as well as the closest lavatory. I provided another printed copy of the consent form (Appendix D) for the participants to sign and reminded them that they could withdraw at any time and pass on any questions they did not feel comfortable answering. I also informed them that they could take a break at any point and that the interview would last approximately one hour to one hour and a half. Using Changing Faces' counselling rooms also meant that participants who had been there before were comfortable doing the interview in a familiar setting.

Conducting my interviews at Changing Faces was very helpful. They were very accommodating when booking rooms and gave me extra time if participants were late. Some participants had never been to Changing Faces' offices and really enjoyed the opportunity to see the charity's headquarters.

Reflections on Interviews

Being a counselling psychologist-in-training meant that it was natural to be in a room with a client and actively listen while making interpretations. Yet I quickly learned that research interviews have many differences and require a substantial amount of skill and practice (Rossetto, 2014). Along with implementing all the relevant therapeutic skills – e.g. building a rapport, being non-judgemental, and maintaining neutrality (Baxter & Babbie, 2003; Targum, 2011) – the interviewer must also maintain focus on their research questions to gain valuable results. It was important for me to be clear regarding my role as the researcher, or role confusion could result (Weiss, 1994), whereby the participant treats the interview as a therapy session (Birch & Miller, 2000). Overall, I ensured I maintained strong boundaries in order to protect the researcher-participant relationship and ethical obligations to do no harm (Dickson-Swift et al., 2006; Haynes, 2006).

Following each interview, I sat alone and noted anything that stood out to me during the interview and any reflections that came to mind. This sometimes meant sitting in silence to process the difficult stories and harsh realities my participants experienced. From the very first interview, I felt very empathetic towards these individuals who lived with an accidental disfigurement. Although I had worked with visual difference for a long time, I found it difficult to shake the strong emotions I felt after hearing some of their distressing stories. In addition to this, I was also aware that I am a young woman without a disfigurement who was sitting in front of the participants. I assumed this would affect the dynamic between us, as many participants spoke about ‘others’ or made comments such as ‘they don't understand’ when referring to those who do not have a facial disfigurement.

Many participants spoke about this freely, and because I am in this category, I had to consider this dynamic throughout the interview phase whilst ensuring I responded with curiosity to inquire further about the participants' views.

For the first interview, I remember being very nervous as I made my way to Changing Faces. I was worried about the participant showing up, as I had previously had one participant who could not make it. I was especially anxious about my interviewing ability and whether I would obtain acceptable findings from these interviews. This later diminished as I built a good rapport with my participants prior to the interviews. I became comfortable interviewing and enjoyed this part the most.

Transcription

Following the first interview, I used a transcription software called Dragon. Although it saved considerable time, it was not accurate in picking up the participants' dialogue. As such, I transcribed the remaining five interviews myself, including all of my own questions, comments, and interjections. As participants shared very personal and touching realities with me, I did not feel comfortable using an external service to transcribe without knowing if it would use password-protected folders or who else had access to the files. This process was extremely tedious but quite helpful, as it allowed me the opportunity to reflect on each interview. I took notes in a research journal (see Appendix J).

Although IPA does not require a detailed transcript such as in conversation analysis, I made clear notes on each transcript whenever there was a long silence using

‘(pause)’, along with any other significant sounds or actions such as ‘uuumm’, ‘ughh’, ‘(cries)’, or ‘(places head in hands)’. This was because I wanted the transcripts to be as close to the original discourse as possible.

Despite the fact that this process was the longest part of my research, it was crucial and helped me immerse myself into the data and the participants’ realities. This would not have happened had I used an external source or software to transcribe my interviews.

Due to the Data Protection Act (1998) and per my ethics, I erased or changed any potential identifying features of each participant, including names they may have mentioned belonging to family members or friends, any hospitals or areas they may have referred to, and any specific identifying features, such as a distinctive tattoo. In accordance to the University of Roehampton’s ethical guidelines, I kept all transcripts, and the digital copies of participants’ signed consent forms will be password-protected and maintained for 10 years, similar to the interview audio files.

Data Analysis

In the initial stages of the analysis, I followed guidelines written by Smith et al. (2009). In sum, I conducted a line-by-line analysis and identified emerging themes. Subsequent development of more interpretative accounts led to key superordinate themes, which are further developed in the following sections.

Reading and Rereading

As Pietkiewicz and Smith, (2012) suggested, I read through the transcripts many times and also used a digital reading software called ClaroRead, which read the transcripts to me. This process was helpful, as it provided me with greater understanding and captured new interpretations. However, following the transcript while listening to the audio in my headphones was the most useful tool during this initial stage of my analysis. As I listened, I made notes of any reflections or anything that I felt had potential significance. Most of this initial notetaking highlighted the use of language, such as metaphors, significant pauses and repetitions, initial interpretative comments, and distinctive phrases and emotional responses (Pietkiewicz & Smith, 2012). I used colour coordination to easily differentiate my notes. For example, blue was used to highlight any descriptive talk, pink highlighted any emotional phases, and purple was used for my interpretations of what participants were saying. Finally, I used green to circle any words I felt were important, e.g. when participants spoke about their disfigurement, they did not always refer to body parts as 'my' but, rather, stated 'this neck' or 'I hated that face' (Appendix K).

Developing Emergent Themes

Once I had completed the initial reading phase, which allowed me to be completely immersed in the data, I followed this step with more detailed notes in an effort to capture the explicit meanings of the participants' experiences (Smith et al., 2009).

Searching for Connections across Emergent Themes

The more detailed notes were used to create emergent themes, which were linked together to establish superordinate themes. This was done by grouping the emergent themes and depended on conceptual similarities and giving each group a descriptive label that appropriately reflected concepts emerging from the text (Willig, 2001). A similar process was used to find emerging themes that could potentially cluster together to create a master theme. A table (see Appendix L) was created to clearly demonstrate how the emergent and superordinate themes were established via examples from the transcripts.

Moving to the Next Case

As suggested by Smith (2009), these steps were repeated for each participant. Interpretative phenomenological analysis relies on idiography, meaning that researchers must focus on one particular case at a time rather than all at once (Smith, Harré & Van Langenhove, 1995). Hence, I had to ensure I remembered that each case was separate and be mindful of the ways in which insights gained from previous analyses could possibly influence my understanding of other cases, which could have led to viewing the case narrowly and missing new relevant insights.

Cross-case analysis

Once the master themes were organised, they were examined for convergence, and this was used to create a list of superordinate and subthemes. All transcripts were reread along with another listening of the recordings to compare the themes for convergence and divergence across participants. The superordinate themes were then used to construct a table of themes (Figure 2).

Overall, I was left with the first superordinate theme 'Shattered self', which included the sub themes 'Person behind the face', 'Aftermath', 'Loss of self', and 'Outsider after once belonging'. Superordinate theme two is titled 'Front seat of identity', which explored the subthemes 'Expressionless', 'Identifying with Exclusion', and 'Separation of mind and body'. Superordinate theme three investigated 'Sculpted self', with the subthemes, 'Made peace with pain', 'Touching death', and 'Integration of self'.

Ethical Practice

This research study followed the ethical regulations of Roehampton University, in line with guidelines from the Health and Care Professions Council and British Psychological Society. Prior to contact with participants, approval for the present research study was obtained by following the procedures of the University of Roehampton's Ethics Committee (see Appendix G).

The ethical issues raised by the project included: informed consent, confidentiality, anonymity, health and safety issues, risk of harm to participants, the voluntary nature of participation, and the possibility of participation withdrawal.

Informed Consent

To ensure that all participants were fully informed of the study's purpose and how the results of their interviews would be used, they were provided with two consent forms (see Appendix D and I) that they had to sign before and after participating in this study. They were also given a signed copy of the consent form to keep for themselves and were informed that they could raise any query concerning the study with me. They were also provided with the contact details of the Director of Studies, who was supervising the research project. The consent form stressed that participant confidentiality would be respected and assured them that all information would remain anonymous, including any potentially identifiable details. The participants were made aware that their data would be held under the Data Protection Act (1998) and would be safely stored on a password-protected USB stick. In addition, I will destroy these files when the research has been completed. All audio-files have been password-protected and will be held for 10 years in accordance with the university's ethical guidelines. If participants wished to withdraw from the study, they could contact the investigator with the ID number provided on the debriefing form (see Appendix I).

The sensitive nature of this research meant that I regularly asked participants for their consent because they may have felt uncomfortable being part of my research once they heard the interview questions or during the analysis stage. As such, I used processual consent (Rosenblatt, 1995) throughout the study to ensure that participants were always aware of the

direction of the research project. This will be continued in future steps of the research, including the topics for the next section of questions (Herr & Anderson, 2014). The use of processual consent was used to ensure that the participants were happy to continue their involvement in the study and reassure them of the option to not answer any question that may have caused distress or discomfort.

Confidentiality and Anonymity

Due to the personal, sensitive nature of this study, the ethical considerations of the research needed to be thoroughly planned and implemented. To protect the study's participants, I maintained full anonymity of their identities via the use of ID codes.

Risk

It was important that the participants knew that they could withdraw from the research, end the interview at any time, or pass on any questions they did not feel comfortable answering. Ensuring that research is collaborative within the qualitative method is crucial, and participants were given the opportunity to address any concerns regarding their participation. They were also asked if they wanted to examine their transcripts to ensure accuracy of their experiences and allow for testimonial validity prior to the study's writing phase (Smith, Flowers & Larkin, 2009). This type of member checking allows researchers to create an accurate portrayal of participants experiences through allowing participants to check the accuracy of interpretations of their transcripts, therefore this adds credibility to the study (Creswell & Miller, 2000). On the other hand, it can be argued that member checking does not add validity to the study due to the power dynamic, participants are highly likely not to want to disagree with the researcher's findings (Buchbinder, 2011).

Due to the sensitive nature of the research, I allowed participants time to share their thoughts on the interview process or project, thereby giving them space to ensure they did not suffer any long-term distress from potential painful feelings evoked by this research. It was my duty as the researcher to terminate the interview if a participant appeared heavily affected at any point (Pietkiewicz & Smith, 2012). I intended to stop interviews should a participant become distressed and draw on my therapeutic training to remain empathetic towards the emotionally intense material that the participants may have shared with me, ensuring that the individuals were treated with great care and thoughtfulness throughout the process.

All six of the potential participants were included, as they were deemed fit by meeting the inclusion criteria (see Figure 1), which required that a participant not be potentially vulnerable, under current psychiatric care, or under the age of 18. All participants were offered counselling at Changing Faces if they felt they needed support or if they became distressed during the interview stage. Details for other services they could contact for support are listed below (also in Appendix J):

Burn Centre Care – 01924.212.332; e-mail: info@burncentrecare.co.uk

Changing Faces – 0345 450 0275; e-mail: info@changingfaces.org.uk

Dans Fund For Burns – 020 7262 4039; e-mail: info@dansfundforburns.org

Let's Face It – 01843 491291; e-mail: chrisletsfaceit@aol.com

Saving Faces – 020 8223 8049; e-mail: info@savingfaces.co.uk

The Katie Piper Foundation – 020 7420 7813; e-mail: ezinna@katiepiperfoundation.org.uk

Debriefing Procedure

Before the interviews began, the participants were thoroughly briefed in person about the study and the types of questions that would be asked, and they were given the opportunity to ask questions or voice any concerns.

Following the interviews, I maintained contact with the participants and returned both the transcripts of our interviews and the findings of the analysis to ensure I maintained their consent. The debrief form (see Appendix I) asks participants if they want a copy of the interview transcripts or a summary of the analysis. If at any point before the final write up a participant does not want their responses included in the analysis, their data will be removed from the study. However, the debrief form clearly states that if participants wish to withdraw once the report has been written, their data may still be used in its collated and anonymised throughout the final version.

Assessing Validity

Yardley (2000) created criteria to help appropriately assess the validity of a qualitative analysis, and Smith et al. (2009) advocated the use of this criteria for IPA. Yardley (2000) established four principles for evaluating validity: 1) sensitivity to context—'Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues'; 2) commitment and rigour—'In-depth engagement with topic; methodological competence/skill; through data collection; depth/breadth of analysis'; 3) coherence and transparency—'Clarity and power of

description/argument; transparent methods and data presentation; fit between theory and method: reflexivity'; and 4) impact and importance.

Sensitivity to Context. The first principle Yardley (2000) outlined is sensitivity to context. The first chapter outlined a gap in the research for a qualitative IPA study on accidentally acquiring a facial disfigurement and the impact this may have on one's identity. The chapter also discussed how this study has been designed to address this gap. Yardley's principle is concerned with ensuring that the analysis is sensitive to the research context, i.e. that the researcher has thoroughly explored the theoretical and empirical literature connected to the research area and has also ensured sensitivity for the participants' data.

I believe that this principle has been addressed throughout this research, as I maintained empathetic relationships with the participants while being mindful of previous literature and the purpose of this research. Morse (1998) addressed the importance of keeping careful consideration of participant involvement at every stage of the research, since it may become difficult to maintain the anonymity and confidentiality of participants' views. This is especially crucial in my research because the participants have had such unique experiences, and even describing their facial differences in too much detail could result in a breach of confidentiality. In line with this, Yardley (2000) noted the importance of remaining mindful of the inevitable power dynamic that occurs between the researcher and the participants. The researcher is the 'expert' in charge and usually benefits from the research. Riessman (1993) suggested overcoming this power imbalance by asking for participants' views on the interpretations made by the analyst.

Commitment and Rigour. Yardley's (2000) second criteria encompasses the commitment of in-depth engagement with a topic; this is not only theoretical, empirical literature but also includes experiences. In regard to this, I have worked alongside Changing Faces for many years, even after leaving the charity, which has given me a breadth of experience in areas such as fundraising, interviewing, campaigning, and counselling. Rigour relates to the 'thoroughness' of the data collected and the 'depth and breadth' of the analysis (Yardley, 2000, p. 219), although Yardley (2000) followed this by explaining that the researcher's imagination and intuition has a higher importance than following set analytic procedures. Smith et al. (1990) added to this principle by suggesting that commitment and rigour can also be shown via the researcher's relatability to participants during interviews and analyses. In response to this, I included an option on each informed consent form that asked participants if they wanted a copy of the transcript and analysis of results before they were submitted, which none wanted. They were all happy to have a copy of the transcript and analysis once my write-up was completed and submitted. Overall, I attempted to remain empathetic and relational throughout this research process, continuously putting my participants first by showing care and compassion in my interviews and analysis.

Transparency and Coherence. This principle refers to the 'clarity of the description of the stages in the research process' (Shinebourne, 2011, p. 26). It was implemented via the detailed steps used to recruit and select the participants (shown under 'Recruitment' on page 47), how interviews were conducted (shown on page 48), and the stages of analysis (page 53). Smith et al. (2009) suggested keeping an 'audit trail' to enhance the transparency and credibility of an analysis. Therefore, I have included appendices with a transcribed interview that shows initial comments and emerging themes (see Appendix K and L), an initial list of themes, and a table of themes from one interview (see Appendix

L). Transparency of this research has also been achieved through the use of reflexivity. I have noted my impact on the research and kept a reflective journal throughout the process (see Appendix J).

Impact and Importance. This last principle states that the true test of validity is whether the research contributes to wider knowledge and understanding within the field. In addition to being well designed and implemented, the final research must be relevant and useful in some way (Smith et al., 2009). I hope that this research aids anyone interested in the perception and experience of identity when an individual has suddenly changed appearance due to an accident. I also hope it is useful for practitioners working with visual difference and for the field of counselling psychology. This was further explored in my discussion.

Overall, as Yardley (2017, p. 2) stated:

> These criteria for good qualitative research are intended to be extremely flexible—there are many ways in which each could be fulfilled; their aim is not to prescribe a particular approach to qualitative research but to help researchers to reflect on and justify the methods they use.

Hence, these guidelines are useful to consider and help justify my methodology, but I am aware that simply abiding by them will not ensure great research.

Analysis

Overview of Chapter

This chapter shows my interpretative phenomenological analysis and brings the unique experiences of this group to life. Throughout this chapter, I will explore three key superordinate themes and associated sub-themes, listed below and detailed in *Diagram 1*:

Superordinate theme one: Shattered self

Sub-theme one – ***Person behind the face***

Sub-theme two – ***The aftermath***

Sub-theme three – ***Loss of self***

Sub-theme four – ***Outsider after once belonging***

Superordinate theme two: Front seat of identity

Sub-theme one – ***Expressionless***

Sub-theme two – ***Identifying with exclusion***

Sub-theme three – ***Separation of mind and body***

Superordinate theme three: Sculpted self

Sub-theme one – ***Made peace with pain***

Sub-theme two – ***Touching death***

Sub-theme three – ***Integration of self***

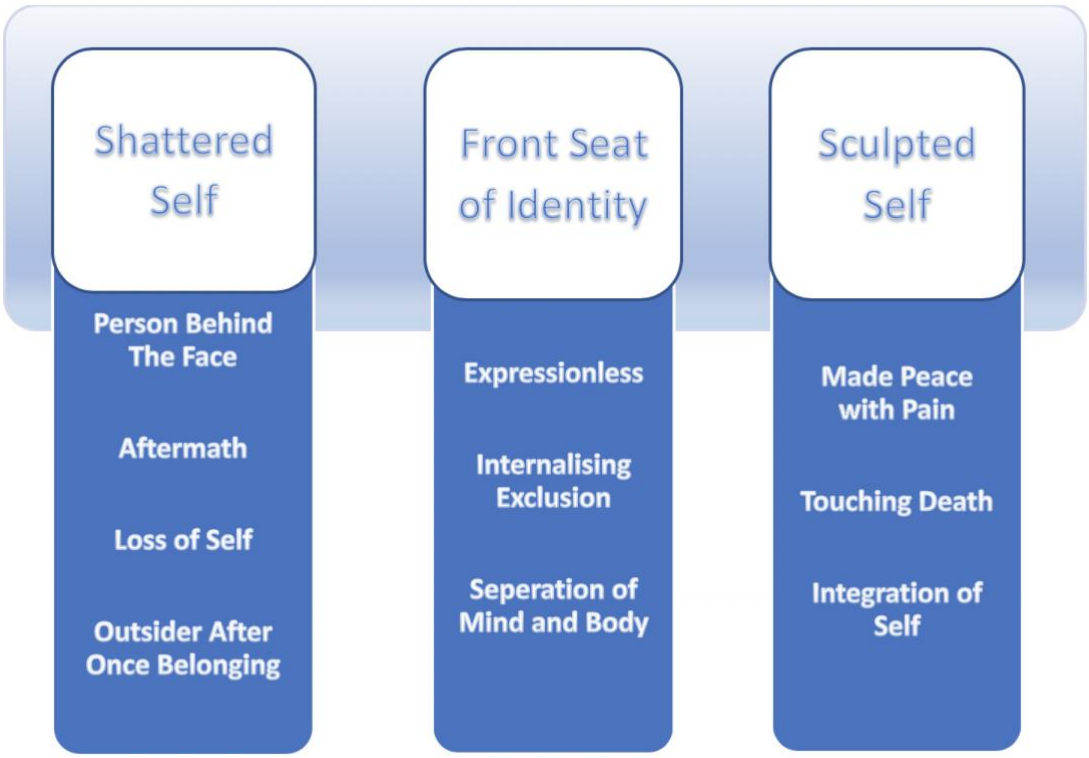

Diagram 1: ***Summary of themes***

It is important to state that although these results aim to capture these experiences of accidentally acquiring a facial disfigurement, it is written from only one perspective and is solely based on my interpretation of their experiences. In order to achieve transparency, each theme is illustrated with direct quotes from participants (Elliott, Fischer, & Rennie, 1999). In typing up each quote, some amendments have been made to bring clarity when reading; for example, 'ermm', 'aaahh', 'hmm' and pauses have been removed. This is unless an unusually long pause occurred or if this break in their talk was important to what the participant was trying to say. For confidentiality and anonymity purposes, any identifying features have been starred out (***) or made pseudonymous. Each quote is followed with the corresponding participant's pseudonym, page and line number so it can be located within the transcript.

Superordinate theme one: ***Shattered self***

As I observed my emergent themes, I noticed many words and phrases that referred to participants' sense of self became fragmented. Therefore, this theme explores this journey of loss and what contributed to this shattered of the self, which occurred through the shock of the accident and becoming an outsider to a world to which they once belonged. Therefore, this superordinate theme aims to introduce the 'person behind the face' of these participants, explore their initial reactions to their accidentally acquired facial disfigurement in 'aftermath', mourn their old self in 'loss of self' and, finally, look at experiences of exclusion in 'outsider after once belonging'.

Sub-theme one: ***Person behind the face***

An important part of this research is exploring how participants described themselves before they accidentally acquired a facial disfigurement. This theme will specifically explore who my participants are beneath their skin. Hence, I will explore who my participants were before their accidents, and more importantly how they saw themselves and their identities before they accidentally acquired a facial disfigurement. This part of the interview was addressed differently by each participant. Some enjoyed talking about who they used to be while others brushed over it quickly and had to be asked directly about who they once were.

Interestingly, the topic of who they were before the accident naturally arose once participants had talked through their accident and how their face had changed. On some occasions I asked, *"Has acquiring a facial disfigurement made a difference to how you see yourself? prompt: If so, how do you see yourself now as different from before you*

accidentally acquired this disfigurement?" (Question 4, Appendix H). However, this prompt question was not always needed, as most of the participants talked about the person they were without my input.

Kiara spoke about her old self the most: *"Hmm wow, who I was, I was very bubbly, naive, life was so invincible, I was invincible"* (Kiara, 4, 177). This suggests that she now sees herself as defeated and is no longer immortal. She continued by saying, *"Going through trauma makes you less judgemental because you gain [an] understanding that everyone has their own journey. It just makes you grow up so fast"* (Kiara, 4, 182–184). She reflected on how she used to be and stated that she was naive to the bleaker parts of life and lacked emotional maturity.

Others reflected less on who they thought they were in comparison to the here and now but more on the characteristics and traits they held before they accidentally acquired a facial disfigurement. Anaya remembered *"Before the accident I was bubbly, the one that was always up for a laugh, up for going out having fun, joking about, dancing about … girly days out shopping... then after the accident it was a completely different world, you know. Before, I would go out take selfies – you know, how girls do. Just a different world"* (Anaya, 5, 126-130). She also reminisced about her unique ways of expressing herself before she acquired a facial disfigurement, *"I'm definitely not the person I was before. I had a laugh. They used to call me Loopy Loo because, you know, my laugh was one of those contagious ones. I had a laugh that made everyone laugh, you know"* (Anaya, 5, 136–137).

Tara also reflected on the positives about her old self and how open she used to be as a person. *"Before this, I argued loudly [and] would say anything and everything to anyone. I*

was a bubbly person. But after, I completely changed – sat at the back and just wanted to be invisible" (Tara, 2, 92–93). Tara experienced a complete change in personality, from being an obvious extrovert to an introvert: *"Before, I used to bring attention to myself by being loud, then I got to a point where I was kind of like, I need to avoid people bringing attention to myself now I look like this"* (Tara, 3, 111–112).

In contrast, Maya saw her old self as constantly tense and stressed, *'I was a very stressed person beforehand'* (Maya, 4, 175–176), reflecting on the negative characteristics she felt she used to have. *"I've changed … I used to put a lot of stress on myself, I had a lot of high expectations for life, and now I think six months ago I dreamt of where I am now"* (Maya, 4, 190–194). On the other and, Cienna did not go into any further discussion or want to explore who she was before her accident as she was very focused on who she had become. She did, however, remember being very in touch with nature: *'I used to love going to the bluebell forest'* (Cienna, 6, 276–277).

Every participant remembered being very different to who they are now and referred to themselves before their accident as *'the old me'* (Kiara, 7, 354), suggesting that the accident changed who they were. This leads to what happened next, the accident, the shock, the trauma and their initial memories of their accidentally acquiring a facial disfigurement.

Sub-theme one: ***Aftermath***

This sub-theme can be described by the process that participants go through right after they acquire their disfigurement. This theme came up naturally in all six interviews and often followed the retelling of the accident. Most of these participants had lost consciousness or had fallen into comas; therefore, they had very vivid memories of the accident. Apart from Cienna, who remembered the whole incident, everyone else only recalled what happened when they regained consciousness.

This part of the interview led to my participants exploring the direct aftermath of what had happened to them and how they faced or did not face their accidentally acquired disfigurement. Participants struggled to confront their altered face. I saw that this was a very important part of their process as they sensed an unrecognisable and drastic negative change to their appearance.

A common theme that occurred in all participants' experiences when addressing the initial aftermath of the incident was that they all avoided looking at their face. Anaya and Kiara did not want to look at themselves for months, and avoided all mirrors: *"I avoided all mirrors, I didn't want to see any mirrors. I didn't want to go anywhere where there were mirrors because I didn't want to see myself"* (Anaya, 3, 80–86). *"They had to remove all the mirrors in my hospital room, I just didn't want to look"* (Kiara, 2, 71). Whilst Anaya and Kiara removed all mirrors in a desperate attempt to avoid seeing their faces, Maya kept her bandages on: *"The first time I saw myself I saw bandages. I had no idea what was underneath the bandages, and I didn't want to know"* (Maya, 6, 270–273). Ellena refused to look at her face until after some surgery, when she felt ready: ***"****I didn't look at my face till after my second operation four days after the surgery… I wasn't mentally/physically and*

emotionally in a good place, so I was like, "I'm not ready to look at my face yet" (Ellena, 3, 133–134). This clearly illustrates that one first difficulties faced by participants after accidentally acquiring a facial disfigurement was confronting their disfigurement.

This was then followed by the intense initial reaction: having confronted their new face, some wanted to be covered back up. *"They made light of what had happened, but when they took the bandages off I had over 50% burns. What I saw was horrible... I just said, "Please wrap me back up"'* (Kiara, 2, 54–64). Maya, however, could not bare being in the dark much longer: *"At that point, I really was realistic… my sister was like, "Oh, it'll be okay, its fine" ... because, you know, people are just trying to be nice to comfort you. But I just said, "Look, my jaw bone is partly missing; this is not going to be okay" ... So it was frustrating hearing "You're going to be okay"; like, no, it actually really sucks, this is just horrible"* (Maya, 6, 283–291). Others mourned the loss of their old face in deep sadness: *"But the only reason I saw my face was by accident and that was about four months after the accident. I only saw my face as there was a mirror in the bathroom on the wall as soon as you come in the door. So, as I got up, I saw half my face and I just broke down, it was awful"* (Anaya, 6, 178–179). *"It was way worse than I would ever imagine. When I finally saw my reflection in the mirror I fell to the ground and just couldn't stop crying"* (Tara, 1, 48–49). All participants had heightened emotion when they confronted their face; this was mixture of shock, anger, sorrow and grief.

Cienna's accident occurred once she had facial treatment, which resulted in a severe eroding reaction that left her skin with a charcoal-black burnt complexion. She had no choice but to face what was happening as it was unexpected.

*Sub-theme two**: Loss of old self***

This theme will explore the journey that the participants took once they had passed the initial aftermath. I further explore the process of grieving the loss of the old self. For some participants, they could pin this down to one moment of realisation: *"A fear of it never being the same as before. That realisation came a little later... once I got home, reality set in, like, 'Okay, this is what I'm going to look like for the rest of my life"* (Ellena, 4, 187–191). Others, reflected on their journey of loss and the torturous thoughts and feelings that came with losing oneself.

Like most participants, Anaya developed a lot of confusion about who she was, which was shown clearly throughout our conversation. When asked, '*Has acquiring a facial disfigurement changed how you see yourself*?' she replied, *"From the accident, I'm a completely different person to who I was... I'm trying to be the old me when I don't feel like the old me"* (Anaya, 4, 129–130). Maya was also surrounded by deep confusion around what had changed in her external world and whether that has impacted on her core internal self, as she questions who she is: *"I have a different smile, I don't feel like the same me. I think at the core I'm still the same"* (Maya, 12, 614–615).

Tara and Ellena both experienced a huge amount of questioning about who they really were and what it will be like living with the loss of who they were. *'Will I even look like me?'* (Ellena ,4, 165), *"I didn't recognise myself. Me: You didn't recognise yourself? 'No, I just thought that's not me, I look completely different"* (Tara ,3, 150–155). For these participants, their embodied self felt distant from their physical self.

Cienna specifically communicated her despair around her loss of identity and who she thought she was. *"It's taken my recognisable facial features and replaced them with something that's just unacceptable, that I can't live with"* (Cienna, 12, 597–598). She is going through this stage of grief by refusing to show her face and accept life will never change or make any sense looking at it this way. *"It's stripped my identity because my face is an extension of who I am... I use a scarf to hide my identity"* (Cienna, 11, 546–547). Cienna not only battled with the loss of her old face but also her heritage and ethnic identity, as her skin colour changed in the parts that were affected. *"It's completely ruined my life. Part of my identity is the colour of my skin and now that's changed, I don't know who I am"* (Cienna, 8, 414–416). Therefore, Cienna is not at the stage of accepting who she is now, although she has acknowledged that she is not the same and has completely lost her old self.

Lastly, all participants reflected on their desire to end their life shortly after they acquired their facial disfigurement. They could not fathom this feeling of despair and hopelessness. *"Actually, I would have rather have not survived than survived. I was in that mindset for a year. They would say, "You're so lucky you survived", but I really didn't feel like that"* (Tara, 6, 274–276). Cienna confessed that she was suicidal: *"I couldn't live. How was I going to survive in this world like this? How can I go on?"* (Cienna, 7, 313). Kiara pleaded her father to end her life: *'I begged my dad to let me go, I couldn't live like this'* (Kiara, 3, 146–147). This highlights the impact that changes to one's face can have on the self, as they all yearned for something to end it all completely.

This theme presents the multiple layers associated with accidentally acquiring a facial disfigurement. This stage of losing the old self is surrounded by suicidal thoughts, confusion, defences and despair. This led me to think about what this meant for my participants'

identities, as Kiara addressed the confusion between two selves: *"The carefree, old me wants to do it but the new voice is more reasonable/sensible and the old you says, "Don't listen to the new you..." You've just got to find the middle ground"* (Kiara, 8, 386–389). She was showing loss and confusion over who she was. Did this loss mean she was the old her with a disfigurement? Or a new integrated self?

Underneath this evidently difficult process lies a huge amount of unprocessed anger, but who is this anger for? Is it for themselves? Their old self for leaving? Their new, tarnished self, or others?

Sub-theme three: ***Outsider after once belonging***

All six participants expressed feelings of becoming 'the outsider' in a world to which they once belonged. This was mainly experienced through how they experienced others' perceptions of them. They all shared harrowing stories of what others had directly said to them, leaving them feeling alienated within their own bodies. Throughout the interviews, I did not ask about the reactions of others, or how they thought society saw their visual difference. Yet, this was mentioned in all of my interviews, some more than others, but it was a distinct theme that each participant intensely worried about; and many then began to see themselves depending on how others saw them. This was, therefore, a very powerful influence on how my participants viewed themselves and their identities (as explored further in 'identifying with exclusion'). I will discuss the main findings that arose as participants explored society's reactions to them and a loss of belonging. This theme will explore questioning one's sense of belonging, inclusion and exclusion in society, looking out for others, issues of boundaries, a lack of understanding and re-traumatisation.

This theme continues to hold much despair and sorrow. Participants become an outsider in a world to which they felt they once belonged. This led them to continuously question others' reactions to them: *'Why is everyone being so nice when I look like this?'* (Anaya, 3, 72). Some felt such a loss of belonging from others that they questioned why some were being nice to them: *'People are nice because of what happened, but are they really being nice?'* (Anaya, 5, 158–159).

Another difficulty these participants encountered was making light of what had happened in order to make others feel more comfortable. *'I have to make light of a situation that isn't light, just to make others comfortable'* (Ellena, 10, 478). Anaya said, *'Outside, I try to put on a happy face for others but inside I'm not'* (Anaya, 5, 144). She went on to share some dismissive comments others had made that also undermined the scale of her experience: *'People say, "You have been through a lot and are still laughing"'* (Anaya, 10, 317). Here, Anaya is expressing this feeling of not belonging, as others do not understand her pain. They naively wonder how she can still be laughing after what she has been through, failing to see that she is just laughing in order to make others believe she is 'okay'. This quote indicates the difficulty of 'appearing okay' to make others comfortable, compared to what she may be feeling inside. Kiara also spoke on this difficulty: *'They were dealing with my scars so I will deal with their pain'* (Kiara, 9, 419). She was trying to manage the burden for everyone around her, whilst dealing with losing the person she used to be: *'The old me died in the fire... Even when I look at old pictures, I don't recognise myself'* (Kiara, 5, 250–256).

Kiara became numb to the struggle of pleasing others and accepted that it is just something that is part of her acquiring a facial disfigurement – *"It's not just for you, it's for*

your family, for society... being [in] society does give you a hard time when you go out there with your scars" (Kiara, 3, 109–110) – although this was something she took years to come to terms with. *"I don't understand why you saved me… look at the state of me, how am I going to live in this society?"* (Kiara, 3, 143–144). She initially saw no way of continuing in this society, as she felt she no longer belonged with her new face. I wondered if she accepted this way of being for others as a compromise for them 'putting up with' having to see her scars. *'Some people will say, "No, you need to stay at home, we don't want to see this"'* (Kiara, 3, 111)). She then said, *'You have to teach yourself and educate others at the same time'* (Kiara, 5, 207–208), as if this is her way of coping with being 'the outsider'.

Cienna shared an experience she had after she found that her breast cancer had aggressively returned. *"The lady at the breast clinic said to the nurse, "I don't want whatever treatment she's having, I don't want a disfigured face". So they put me in a side room so that I didn't upset or worry the other patients"* (Cienna, 9, 459–461). This experience highlights the re-traumatisation that individuals with an acquired facial disfigurement may encounter in some form as society desperately tries to protect 'others' from their face. Cienna also had a hurtful conversation with a woman who said, *'"Oh, did you get your face done here for Halloween?" I just burst out crying at the thought that someone thought I had done it to scare people'* (Cienna, 7, 344–346). As I listened to these stories of other people's reactions to Cienna's altered appearance, I thought about the lack of knowledge on different conditions. This is something that Cienna expressed when I asked what 'disfigurement' meant to her. I sensed anger and rage in her tone, and maybe some jealousy for those who had general conditions about which everyone has knowledge. *'More knowledge on inherited conditions like a cleft palate. No one understands my face'* (Cienna, 11, 525–523). I felt her deep sadness as she explored society's reactions to her face: *"Everyone in society has been*

very negative and has made it so much harder. It means that I haven't accepted myself and I don't think I ever could" (Cienna, 10, 514).

This leads to the question of boundaries, which some expressed more than others. Ellena was particularly passionate about this topic: *'I completely lost my privacy'* (Ellena, 7, 325); '*never get used to people looking at your face'* (Ellena, 5, 217); '*make people feel like they have something to start talking to you… it's the most profound thing people notice... my defining feature'* (Ellena, 6, 311). She voiced that she needs *'a break from being myself'* to avoid the intrusiveness from others. She felt huge pity, as though others were only commenting to satisfy their ego: "*They think they have done something profound by telling me something altruistic. They feel like they have done something good by being nice to the girl with the scar on her face"* (Ellena, 7, 335–336).

Maya sand Tara also shared a similar desire to have a break from herself because of others' reactions. *'You can't just hide your face for a day'* (Maya, 3, 124). Her difficulties began as she wanted to go out and make the most of her life, despite having experienced such a severe accident; however, she felt that other people's reactions prevented her from doing this. *'I can ignore it by not looking in the mirror, but then someone will just look/stare or comment and ruin my whole day'* (Maya, 8, 412–413). Tara also wanted a break as she went back to school after her jet ski accident. *'I wanted to go into hiding but I was forced to go back to reality'* (Tara, 3, 121). She felt exposed as she returned to school and felt she had *'to tell others [rather] than hear rumours about my face'* (Tara, 7, 355). Relating to Kiara's experiences of educating others, Tara felt a duty to justify herself in order to avoid others making their own assumptions about her face.

The lack of knowledge about accidentally a acquired disfigurement led participants feeling a sad weight of alienation as no one understood them: '*Everyone's going to hate me, no one's going to come near me, they'll think it's contagious'* (Kiara, 1, 78–79). Similarly, Tara neglected her pain and loss of self but clung to the worry of how she would be treated by others: *"I didn't think about the here and now but more about the future. Could I go back to school? Will I need to go to a different school? I thought a lot about my friendships… will my friends want to stay friends, or will they see me as different?"* (Tara, 2, 65–68).

This theme displays the huge difficulty that 'others' create for all six participants, preventing them from coming to terms with their accidentally acquired facial disfigurement. This theme is overshadowed with loneliness, alienation, isolation and social exclusion as they felt that no one understood their face.

Superordinate theme two: ***Front seat of identity***

This superordinate theme differs from the rest as it explores identity in relation to the face. This addresses the exterior physical body and face in relation to the internal self. In contrast, I previously addressed the self as character and what someone is like inside, i.e. how they feel and think. Therefore, this theme will uncover the links found between the face and one's identity. To begin with, I will explore the face in its expression, and how participants struggled to physically show their emotions due to restrictions in the face leaving them 'expressionless'. The second sub-theme, 'identifying with exclusion', will delve into how participants internalise others' reactions, as explored above, and how it has impacted on their identity. Lastly, the 'separation of mind and body' will uncover ways participants begin to

view their mind and body as two separate entities rather than in joint union, as suggested in the literature.

*Sub-theme one – **Expressionless***

A core theme that arose throughout all interviews was the ability of participants to accurately portray their emotions through the physical expression located on the face. For these participants, this was mainly due to severe nerve damage, skin grafts or paralysis.

Furthermore, participants not only had to adjust to acquiring a facial disfigurement, but also had to adjust to difficulties they now encountered when attempting to communicate and express themselves, through the face. This was unexpected for most participants and impacted some more than others, depending on the severity of their loss of expression. Maya explored the important role the face plays in communication and expression: *"The face, to me, it's a very important part of who someone is and I don't mean it defines someone but it shows a lot your expression, and your face is what people look at. It's where you make eye contact from and stuff and you can't cover it up. I don't care about my leg scars because people can't see it whereas everyone can see my face"* (Maya,3, 111-115). She particularly struggled with expressing her joy: *'I couldn't laugh… It's tough to think, but even if I wanted to laugh I couldn't.' Me: And that's when you stopped being able to express who you were?'* (Maya 13, 628-630). Not being able to express something such as laughter left Maya feeling like she could no longer express who she was.

Many did not think they were the same person because they could not express themselves in the same way they used to through the external boundaries of the face. *'A smile is something that it kind of defines your face and so when your smile has changed… and you*

see a picture you just [go], "Oh", then you think "Oh, like that's not me"' (Maya, 10, 497-499). Ellena felt like a different person inside rather than the one she was reflecting on the outside: 'If I'm raising my eyebrows or doing something I'm like*, "Oh, both your eyebrows aren't moving, oh, maybe I'm not making the facial expression I think I'm making", so I have to think about that now'* (Ellena, 10, 408-410). This has meant she has to learn her face again and what it portrays with different expressions: *'So now I have to think about it. I look in the mirror and think, "Oh, this is what I look like when I think I'm making this face"*' (Ellena, 9, 418-419). For Ellena, her expression was such a fundamental part of her that she considered refusing Botox in order to preserve it, risking how successful her recovery would be: *'I can only move one eyebrow'. Me: So something that may have changed is the amount of expression? 'Yeah, yeah, and now they want me to get Botox and I think, "Well, I want to preserve the little expression I have left on my face"*' (Ellena,8, 386).

Along with a lack of expression, some participants also lost senses that are located on the face: '*A lot of my face is numb, my breathing I can't… I have to sort of breathe through my mouth… I can't really smell anything'* (Anaya, 1, 7). Tara lost her hearing as a result of her accident: *'the main thing I still struggle with is my deafness'* (Tara, 5, 230). Tara also struggled with seeing – '*my eyes were almost swollen shut, I had a very obvious slant at the side of my mouth'* (Tara, 1, 39) – along with eating and drinking, which is *'so difficult and it's hard to use children's cutlery; I had to use sippy cups. It was so difficult'* (Tara, 5, 227).

Whilst some participants did not lose their expression or senses, they did not want to be seen at all; hence, they covered their full face and thus in turn masked any expression and some senses: *'I've had my hood up and scarfs across my face and that's how I disguise myself. I walk around and constantly disguise myself… It's taken away my recognisable*

facial features and replaced it with something unacceptable, something I can't live with' (Cienna, 12, 597-598). Directly after their accidents, Anaya and Kiara also covered their faces in public.

Overall, this theme addresses the importance of one's physical face in our expression and senses. Due to participants having accidentally acquired facial disfigurement, this not only meant a change in appearance but also the inability to visually display what they thought and felt along with how they sensed the world around them.

Sub-theme two – ***Identifying with exclusion***

This theme explores how participants internalised what others thought of them and how this impacted on their identity. Many changed their everyday life because of what some people in society had said: *'I was unable to go on a job interview or meet new people. I didn't have to constantly think, "Oh, they're wondering what happened to my face" in everyday interactions. I had to wonder if people are looking at my face'* (Ellena, 5, 249-254). Some changed their lifestyles because of how they assume others perceive them: *'I wonder how people perceive me. Now, I constantly think about it whereas I didn't think about it before*" (Ellena, 8, 387-388).

This was evident throughout all interviews; participants had certain ideas about how society perceived them. This was based on negative interactions and their ideas around what society feels is an 'acceptable' way of looking. Kiara assumed the worst after many awful comments and negative reactions to her visible difference: *'[I] just thought, "Everyone's going to hate me, no one's going to want to come by me – they'll think it's contagious". It*

was just awful' (Kiara,). Anaya admitted that this was not always what had happened, but she internalised this negative image of her to society and avoided going out because of these thoughts: *'I don't go out with friends… it's not because people were looking at me but because I thought people were looking at me'* (Anaya, 4, 113-114) On this note, when asked what disfigurement meant to her, Maya replied *'a disfigurement to me is something that's noticeable to other people'* (Maya, 11, 529); hence, she believed that a disfigurement is judged by society rather than by the individual.

Many internalised these opinions of others and believed them to be true: *'this woman told her child, "Don't look at her, she's ugly, she's horrible…" And I was horrible... I just sort of put in my head "This is what people think of me"'* (Anaya, 8, 234). I noticed that this was the case for most of my interviewees and is still the case for Cienna: *'I'm always so desperate to cover my face from the world… to hide my identity'* (Cienna, 4, 181). She has internalised who she is in the eyes of others and believed this to be true: *'I'm a freak, I'm a freak of nature. I don't see anything else now, that's all I see'* (Cienna, 12, 605). Initially, Tara also tried to be invisible: *'I was trying to get people not to look at my face. I went into hiding, I didn't volunteer for things and draw attention to myself'* (Tara, 3, 111). Interestingly, Tara said she had only accepted herself when she felt others had. Most of the people around her had not known her before her facial disfigurement, *'So to them its normal. So if it's normal to them, it should be normal to me and that's how I see it'* (Tara, 4, 209–210). Although positive, Tara still defined herself depending on how others reacted to her face.

This theme highlights the importance of one's outward appearance as this is the only visible representation that is shown to the world. As a result of this, when the face undergoes

a disfigurement, society views it as '*unacceptable*' (Cienna, 12, 598), leaving individuals feeling excluded. Participants internalise this negative projection into their identity.

Sub-theme three – ***Separation of mind and body***

This theme looks more closely at the separation of the mind and face. Throughout my emergent themes, it became apparent that participants' main struggle was accepting that this face belonged to them. They could not look in a mirror; hence, they did not want to accept that this facial disfigurement was the now, a visual representation of their identity.

When asked what major changes occurred, all participants mentioned physiological factors such as breathing followed by psychological difficulties: *'I would say my breathing, the face and definitely my mood; defiantly, it's sort of affected my mood a lot'* (Anaya, 2 , 9). Participants' biological progress seemed to be focused on before anything psychological was, and both parts were addressed separately throughout my interviews. Ellena and Cienna spoke about the medical aspects of their altered appearance for approximately 20 minutes then addressed the psychological difficulties they faced as a result of accidentally acquiring a facial disfigurement.

This theme was created by looking further into how participants addressed their body. For example, many did not use the term 'my' when addressing their physical self: *'It has been traumatising to look in the mirror and see this'* (Anaya, 6, 178–179). Anaya refers to her face as 'this', showing distance between who she feels she is and who she is on the outside. Similarly, Kiara uses the term 'it' to refer to her skin and 'the' referring to her neck: *'It's tough to live in a skin that you're not familiar with, because it's constantly changing… I*

think this is the sixth neck.' Me: I notice you call it different necks not 'my neck'; is it distant to you? 'Yes, yes' (Kiara, 5, 217-218). Therefore, this participant is rejecting the face and other body parts from the self.

Others also struggled to accept that their physical self was part of their inner world: *'It took me a while to get used to like seeing pictures of myself'* (Ellena, 4, 202). This occurred with small changes in physical appearance: 'I got new dentures… and they accidentally made them a millimetre too short but with your face, and if you've had certain teeth your whole life – that tiny, tiny difference – and if all of a sudden that changes then you're like, "*Oh my god, that's not me"*' (Maya,10, 492). Cienna's skin colour completely changed, leaving her more confused about who she was: *'It's me, it's the colour of my skin, it's changed my identity'* (Cienna,8, 414). All participants felt distant from what they saw on the outside. As explored in 'Loss of self', participants initially rejected their face and exterior after accidentally acquiring a facial disfigurement; hence, they developed a separation of their perception of their identity on the inside and what they saw change on the outside.

For some, accidentally acquiring a facial disfigurement meant that they no longer recognised themselves: '*Now, I sort of like look in the mirror and I'm like, "That's just me, that is who I am". At the time, it would sort of... I didn't even recognise myself.' Me: You didn't recognise yourself? 'No, at the time, for about three years, I just thought, "That's not me, I look completely different"'* (Tara, 3, 153-155). This also occurred with close family members: "*The night of the accident, my mum came into the hospital, but she didn't know who I was, she couldn't recognise me, and the only way she recognised me was by a ring on my finger I wore. But if I hadn't had that ring, she said she wouldn't have known who I was"* (Anaya,3, 68-70).

Finally, Maya felt as though society had also separated her mind and body by treating her as though she is just her physical self: *'This is a year and a half of struggle but people can be insensitive… and forget you're a real person. Then you say, "Oh, hi", and they wake up from their staring and think, "Oh, she's real, she's alive"'* (Maya,9, 462-463). This is an important quote as it explores the idea that if the face is 'different', society reacts to it as if it is detached from a mind and identity.

In conclusion, this theme explores the notion that identity is a combination of both mind and body. This is shown as these participants experienced a threat to their identity once their exterior had changed. An important aspect of this theme is that it explores society's reaction to acquired facial disfigurement, which is to desperately 'fix the face', making it more 'acceptable', rather than integrating and valuing the mind and body equally.

Superordinate theme three: ***Sculpted self***

The 'sculpted self' explores how each participant perceives their identity, having gone through and processed the loss of their old selves. The first sub-theme, 'made peace with pain', will discuss how participants dealt with their suffering and came to terms with their loss. This is coupled with a search for meaning after 'touching death', when participants found value in living. Lastly, 'integration of self' is a key theme that will show how participants have either integrated both their old and new selves or completely rejected the merging of a new self.

Sub-theme one: ***Made peace with pain***

'There's the pretty side to it (the healing over time), the ugly side to it and then the accepting side' (Kiara, 6, 286–287). Here, Kiara has simplified a journey that, as we have discovered, has many ripples. She explores her journey, and through this explains that she is now at the process of accepting her new self. However, she is also aware of the painful parts of her route to acceptance, showing that she is more at peace with her loss.

On the other hand, some participants made peace with pain through reflecting on the strength needed to be where they are today: ***'****It made me who I am and much stronger. It's what's on the inside not the outside'* (Anaya, 6, 182–183). Maya also appreciated the colossal strength she needed to endure her facial disfigurement: *'This is not just a scar, there's a whole story behind it, behind me'* (Maya, 9, 436–438).

Tara demonstrated this, as she initially stated that, *"these aren't just scars… they're like my battle scars and a lot of people wouldn't have survived what I did. I'm a miracle, really"* (Tara, 5, 248–249). When I asked what she would have said if I asked her at the time of her accident, she replied, *"I would have said it was the worst thing to ever happen to anyone, and it wasn't a miracle at all. At the time, I thought it was utterly disgusting – or that's what I would have said***"** (Tara, 5, 262–264). Therefore, this suggests a positive shift in her thinking and how she viewed herself after accidentally acquiring a facial disfigurement. Although this was an extremely long process, *'It took a really, really long time before I could actually accept that this was me. Full acceptance took about four years'* (Tara, 4, 159–162).

Participants identified with being survivors: *'This is me, I am this, this is who I'm going to be and it's not going to change'* (Anaya, 6, 196–197). For some, this was for the sake of those around them: *'I made peace with pain; they can't do that'* (Kiara, 9, 427–428).

Although five of my participants encountered a similar process of finding a more peaceful way of living by embodying this new identity as their own, Cienna did not. **'***What is the point of going on anymore? I can't go on looking like this'* (Cienna, 10, 475–476). Therefore, she refused to accept her face as part of her identity.

Sub-theme two: ***Touching death***

The search for meaning in life is a topic that emerged throughout my interviews. Participants talked a lot about how serious their accidents were and how close they came to 'touching death'. They all questioned their existence, and many went on to explore what their life meant. For most of my participants, their accident and the changes that came with it gave them a new sense of perspective and meaning.

Tara saw life differently after her jet ski accident, specifically because she had argued with her mother and sister prior to the accident: *'I just kept thinking about my argument with them'* (Tara, 1, 51–52). She shared the impact that this argument had on her as she woke from her coma. All she could think was that life was too short and precious to stay angry as she may not have had the chance to reconcile with her family had she not come out of her coma. *'It was a miracle, the doctors said. My injuries were so bad they were surprised I survived it'* (Tara, 5, 249–250).

Maya enjoyed talking about her new-found meaning, as she simply began to appreciate her being in the world: *'Now I actually have something important, like life-threatening, to stress about, it puts everything into perspective'* (Maya, 4, 176–177). She shared her reasons for wanting to live a more fulfilling life. It was due to her accident, as it helped her see what she wanted in order to make the most of what she had: *'After my accident, as clichéd as it sounds, I appreciated so much more about my life and I just really wanted to make the most of it'* (Maya, 3, 129–130). She went on to say, ***'****I could be really stressed about something then look up at the sky and realise it's actually a really, nice day'* (Maya, 4, 171–172). However, she confessed that she does not see everything this positively all the time: *"You realise it could be worse, but you can't use that for everything or you'll avoid all your actual emotions that you feel. But it helps me put life into perspective"* (Maya, 7, 344–346). Therefore, her new-found appreciation for life has meant a change in herself, as she no longer feels worldly stresses or keeps unnecessarily high expectations for herself.

Participants found meaning in their survival; yet for some, this came years later. *"You have to change once you go through trauma. You never look at life the same way... you can either become bitter or rise above it"* (Kiara, 3, 130–135). Anaya said that *'[i]t makes you a better person, but it makes you realise that life is worth living because you just know that it could suddenly end. I mean, now I make the term I said I wasn't going to make it, I'm still here... You never know what's around the corner so you've just got to make the most of everything you have and every little thing, or be thankful for every person you have, and it changes a lot of things'* (Anaya, 10, 330–334). These quotes show a profound shift occurred as the participants began to see themselves as survivors. This changed their outlook on life profoundly.

On the other hand, Cienna did not view herself as a survivor, which may have been due to the nature of her disfigurement. Even though her accidentally acquired facial disfigurement was life-threatening, with her skin eroding as she suffered a severe allergic reaction to a cosmetic procedure, this reaction happened over a period time rather than all at once. The uncertainty of 'will I survive?' lasted many days, as she had to patiently wait to see how the allergic reaction would manifest itself. I was also saddened to hear that after many years of living cancer free, Cienna's cancer had returned: *"I found another lump on my breast after surviving cancer. I told my GP I couldn't go to the hospital with this face… I didn't want treatment"* (Cienna, 9, 422–424).

Sub-theme three: ***Integration of self***

This is an important theme that draws together the essence of my research. Whilst the 'separation of mind and body' discusses the split between participants' physical and internal selves, this theme discusses participants merging who they were before and after their accident. Therefore, this meant a merging of mind and body.

Kiara shared both positive and negative memories of who she was: *"I'm not very cynical, I'm calmer. I was quite hyper and all smiles, I never used to give anything a second or third thought... now, I'm constantly deep in thought"* (Kiara, 4, 192–196). She now reflects more on her old self: *'I like to think I wasn't judgemental, but I probably was'* (Kiara, 4, 128). Her talk indicates that she is now different to the person she is describing as her old self.

This was confirmed as she went on to talk passionately about this notion of having to integrate her two selves. She struggled to integrate her old self with the new as she lost some of her past memories of who she was: *'I forgot I had a daughter, husband. My life, my memory, went back to when I was 14/15. I was 23... I don't remember what my face looked like'* (Kiara, 1, 33–42). This may have had a huge impact on Kiara's experience as unlike the others she no longer remembered the old her. This also meant she struggled to integrate but later accepted that this was the process she had to go through: *"You never will feel like the whole you; I still don't feel me... that part of you died that day and then you have to reinvent yourself. I've reinvented myself so many times in the past year; but if you don't, you won't be able to mentally cope with it"* (Kiara, 3, 104–108). Kiara spoke about her journey towards this integration and said, ***"****It's tough to live in a skin you're not familiar with... and you don't get familiar with it because it changes all the time, so you're constantly changing yourself"* (Kiara, 5, 215–218).

Similarly to Kiara, it seems that many of my participants saw themselves as two parts, the old and the new, with the need to integrate the two: *'I have two selves, the old me and the new me'* (Kiara, 5, 152). Again, similarly to Kiara, Anaya found it very difficult live peacefully with her new, integrated self: *'I don't feel like the old me'* (Anaya, 5, 152). She also acknowledged this change as she stated *'I just broke down, it was awful. I went from one person looking like I did, to this person'* (Anaya, 3, 85). Like the others, she had a confusing process of integrating the two selves. This confusion showed throughout our interview as she started by saying *'I'm still me… I'm just going to be me with a couple of scars'* (Anaya, 9, 217–272), before moving to a more confessional tone: *'I'm desperately trying to be the old me but I'm not the old me'* (Anaya, 5, 152).

Anaya also changed her language during the interview. To start with, she referred to her face and self in the third person, using terms like 'the disfigurement' or referred to her face and disfigurement as 'it'. As the interview progressed, she addressed it as part of her: *'I couldn't believe it was me'* (Anaya, 3, 87). Although she is still in denial, she refers to herself as 'me', beginning to acknowledge that it is part of her. She moves from being alienated from herself to acknowledging that she is a mix of her old and new self. As she flows between the third- and first-person tenses, she shows us that she is in the process of integration.

Tara and Maya had a different experience and way of looking at their identity after their accident and facial disfigurement. Tara was coming to the end of her academic journey and was starting a new life as she entered the workforce. She explained that this meant that most of the people she knew now have only ever known her like this, with her visible difference. This aided her integration of self as she accepted herself as others did; and, as explored above, in the 'outsider after once belonging' section, all participants faced the struggle of seeing themselves depending on what others thought of them and the huge part that this played in their journey. Tara was reflective about this and saw that she wasted time worrying about what others thought of her: *'Such a long time to not accept something that I can't change. I wasted so much time neglecting myself'* (Tara, 4, 163–164), she said, rather than accepting her new self.

Maya was also very reflective and saw her experience differently in hindsight: *"I've really changed. I used to put a lot of stress on myself. I had a lot of high expectations for life. Now, I think six months ago, I dreamt of where I am now, being able to go out with my scarring"* (Maya, 3, 192–193). She experienced her new self as positive; therefore, she did not see a huge loss in her old self as she appreciated life and changed her outlook, which gave

her a new lease of life. She saw life as more than just material things and fighting for achievements; she was now released from these worldly things, freeing herself from expectation and simply valuing life itself. As explored above, Maya was very rational: *'even if it completely heals, it will never be completely gone inside'* (Maya, 8, 339). However, she saw the positive side of her new self and accepted that her old self will never completely go away and will be forever there inside.

Cienna's experience was very different to Maya's. Even though much time has passed, she struggles to live her day to day life since her facial disfigurement, demonstrated by her loss of desire to look after herself: *'I haven't bought any new clothes in a year, I have no interest, I don't want to dress up and I won't look nice. [I've] just given up on myself'* (Cienna, 9, 451–452). This shows that the type or severity of facial disfigurement had no impact on the amount of time it took participants to accept their new face, and it is purely a personal experience that is heavily varied, dependent on each individual.

Subsequently, all participants bar one integrated their mind and body through accepting their new face. As shown through this chapter, this process was very long, as Tara confirmed: *'I don't think I fully, fully accepted myself till my last hospital appointment, which was last month. [It] wasn't till then that I fully got to a stage of full acceptance, which took four and half years'* (Tara, 4, 164-166). Overall, it can be concluded that the coupling of mind and body is what occurred in order for participants to accept a new integrated self.

Discussion

Overview

This final chapter will outline the results gathered from the Analysis chapter, looking at each theme and how it widens our knowledge and awareness of the experience of accidentally acquiring a facial disfigurement and identity. It will then focus on the complexities of accidentally acquiring a facial disfigurement and how counsellors and psychologists can effectively and therapeutically meet the needs of these individuals. I will address methodological considerations and reflexivity, along with limitations of the methodology and results from the present study. Finally, I will explore the significance of this research and suggest directions for future research.

This research aimed to address how accidentally acquiring facial disfigurement can affect the perceptions, perspectives and experiences of identity for individuals. I am aware that the results gathered from this research are only relevant to this limited, homogenous sample. This research does not set out to make claims for larger populations; as it uses an IPA methodology, it aims to only inform the in-depth experience of this particular group, as a starting point for further investigation (Smith et al., 2009).

Summary of Results

To begin with, I created three superordinate themes that I captured from the interviews. These were ‘Shattered self’, ‘Front seat of identity’, and ‘Sculpted self’.

The first superordinate theme, 'Shattered self', analysed how participants referred to themselves before they accidentally acquired a facial disfigurement. This theme found that participants referred to themselves using past tense '*the old me*', as if they were not the same person. This theme continued to explore the 'aftermath' where participants rejected their face, wanting it to be covered back up and avoiding all mirrors after acquiring a facial disfigurement. Following the initial aftermath, participants experienced a 'loss of self', where they mourned the loss of who they were with their old face. This theme ended with the added struggle of becoming an 'outsider after once belonging'. This highlighted the intense pressures that each participant felt as they attempted to re-enter the world with their altered appearance. Each participant experienced being bullied and treated like outsiders in a world in which they once belonged. Overall, this experience was overshadowed by alienation, isolation and social exclusion as they all expressed deep sadness and loneliness, as no one understood their face.

The second superordinate theme, 'Front seat of identity', discovered the relationship between the face and identity through expression, internalised exclusion and the separation of mind and body. 'Expressionless' covers participants' struggles with not being to express themselves in the same way they used to; this led them to feel distant from their face as not only was it different but also it did not serve its function of expressing their inner emotions. Another component of this theme was 'identifying with exclusion'; this showed participants internalising what others had said into their own perceptions of their identity. The final subtheme within this superordinate theme explores the 'separation of mind and body'. As a group, participants all experienced a separation between their outer physical self from the internal mind. As they rejected their face after accidentally acquiring a facial disfigurement,

this left them estranged from their physical exterior bodies. Therefore, this superordinate theme shows the significance of the face in relation to identity.

Finally, superordinate theme three, 'Sculpted self', encompasses each participant's journey of re-sculpting their identity to include their old and new selves. This was shown through the need to 'make peace with pain', which meant participants endured their suffering and came to terms with their loss, which in turn shaped a new self. Eventually, participants integrated their experiences of accidentally acquiring a facial disfigurement into their identity. This arose from the intense experience of 'integration of self', creating a new meaning of life. This new meaning enabled five participants to integrate their mind and body as part of their identity. This was a huge factor in their journey to recovery, and it was particularly difficult for one participant who could not pass this stage of integration.

As I immersed myself into the data, I noticed a pattern through my emergent themes: the stages my participants were experiencing related greatly to the process of loss and grief, according to Bowlby and Parkes (1970). The first stage, 'shock and numbness', was clearly felt in the 'aftermath' as participants struggled to see their face and wanted to avoid it. Participants then entered the 'yearning and searching' stage of grief. This was explored in 'loss of self', as participants yearned for who they once were and desperately searched for answers like, 'Why me?'

'Made peace with pain' guided us through the 'despair and disorganisation' stage of mourning, which involved coming to terms with the loss of who they were. They all experienced yearning and searching for their old self, desperately trying to keep parts of who

they were alive and not being ready to accept their new face. Some were stuck with feelings of hopelessness and despair while others were left questioning and blaming.

The final stage of grief, 'reorganisation and recovery', became clear throughout the theme 'Integration of self'. As the reorganisation and recovery stage of mourning suggests, participants attempted to restore faith in living without their old self through valuing the strength needed to survive their shocking experience. Apart from one participant, who was stuck in the 'yearning and searching' phase, all participants come to realise that life could still continue, even after their loss.

Overall, these key findings follow participants' journeys from losing their old self and separating their mind and body as they reject their new face, to dealing with society's negative reactions and finally integrating their experience of acquired facial disfigurement into their identity. Therefore, these findings give us an in-depth understanding of the experiences, perceptions and perspectives of accidentally acquiring a facial disfigurement and its impact on one's identity.

Contextualising the Main Findings in the Literature

Shattered self

A key finding that arose from my analysis was that participants felt a 'loss of self'. This has been heavily researched throughout the chronic illness literature and among head and neck cancer patients (Charmaz; 2002; Fife, 1994; Osborn & Smith, 1998). Yet, the research has not been in-depth apart from that of Turpin et al. (2009), who studied facial

disfigurement from the onset of head and neck cancer. Turpin named this the ‘destruction of self’.

Throughout this theme, Turpin et al. (2009) also found that seven participants felt a loss of their valued roles in society, such as occupation, this impacted my participants during the aftermath but was not something they raised much in the interviews, apart from Cienna, who is completely socially isolated. These differing results may have been due to the nature of their visible . The participants in the study by Turpin et al. (2009) had all been diagnosed with cancer and were in the treatment phase, meaning that their recovery could take longer; in addition, the treatment can be so rigorous that it could be physically impossible to work with such a life-threatening condition. This was not heavily experienced by the participants within the present study, which may be due to the nature of head and neck cancer diagnosis as opposed to accidentally acquired facial disfigurement, as participants could continue to work and fulfil roles, including being mothers or wives and even continuing in occupations.

Similarly to my theme the ‘outsider after once belonging’, Turpin et al. (2009) established the theme of ‘disenfranchised self’. This theme addresses the difficulties of being ‘different’ and being excluded from society, exploring a loss of privacy and feelings of being overexposed. However, these themes differed as the ‘disenfranchised self’ goes on to explore similar difficulties within participants’ intimate relationships, whereas my study focused on the shift of becoming excluded from a society to which the participants once belonged and how the participants changed their way of life depending on how others perceived them.

Additionally, this was supported by existing literature on young adults with visible facial differences. Beak (2015) found that participants were viewed by society as ‘different’,

experienced explicit social rejection, reported a lack of self-confidence, and lost a sense of privacy, as they were repeatedly asked intrusive questions. Throughout my analysis, I have highlighted very similar barriers that my sample of adults aged 16–65 faced; therefore, this adds to the pool of research on the complex difficulties that may come with acquiring a facial disfigurement.

Beak (2015) also concluded that participants experienced a 'fragile sense of self' as they attempted to adjust to their disfigurement. They had the challenge of dealing with others reactions, requiring them to use increased psychological effort to maintain a positive sense of self. However, Thompson et al. (2002) stated that this is evidently not always possible, as shown throughout my analysis by one participant who struggled to maintain a positive sense of self and accept their acquired disfigurement.

Front seat of identity

Superordinate theme two, 'Front seat of identity', looked more closely at identity in relation to the face. The subtheme 'expressionless' supported the idea that our inner self can be seen through expression on the face. Similarly, Aristotle's *Physiognomy* suggested that the face and expression can determine characteristics of the mind. Although this research did not focus on facial features or expressions when determining one's character, it did explore the experience of losing some facial expression. The findings from this research, therefore, support the notion that one relies on the face to express parts of one's inner world. This theme also finds the impact of losing senses through the face; as discussed in the literature review, these are critical physical entities that we use to investigate the world (Rudge, 2009). As these participants experienced a loss of expression and senses, we can see the detrimental

impact this had on their on their sense of self, highlighting the importance of the face and one's identity. This has not been researched much within the discipline of counselling psychology.

My literature review also posed the question 'what happens when the structure of the face is unrecognisable or redefined in any form – is an individual's identity reduced or changed?' It could be argued that each participant's identity changed as they could not express themselves in the same way they used to, leaving them feeling distant from their face and separating the body from mind.

This superordinate theme also touched on our recognisability and how some participants could not be recognised by loved ones or themselves, this highlighting the importance of being able to recognise each individual and unique face to determine one's identity. The subtheme 'identifying with exclusion' is similar to Turpin et al. (2009), who created the theme 'disenfranchised self'; this theme explored the challenging experience participants had of facing society. However, this is explored in further depth within the current study as it was not simply others' reactions to their face, as explored in 'outsider after once belonging', but went deeper into how the face can influence how we see ourselves internally, through how others perceive our exterior.

Similarly, Turpin touched on the separation of mind and body as participants with head and neck cancer also referred to parts of their body as 'this' or 'that' rather than 'my'. Yet, Turpin did not explore this much further, whereas the present study devoted a subtheme to this crucial finding, which discovered that participants paid more attention to the body and physiological treatment before attending to the mind and any psychological difficulties. This

theme went on to uncover participants' separation of mind and body as they struggled to look at photos of themselves and felt distant from their bodies, mainly their faces.

Sculpted self

These studies, however, also differ from the present research through how they view the 'integration of self'. These studies address this as the 'conservation of self' (Turpin et al., 2009) and the 'positive sense of self' (Beak, 2015). These studies also explored participants coming to terms with their disfigurement and being less influenced by the opinions of others. In contrast, the current study found that this was not always the case, as seen in Cienna's experience.

Most described their disfigurement as part of who they were now and how acquiring a facial disfigurement had shaped their personalities and made them who they were today (Beak, 2015). Similarly, Turpin et al. (2009) named this the 'conservation of self', which analysed how participants eventually constructed valued identities of themselves as survivors through developing a more positive sense of self, as in 'made peace with pain' and 'touching death'. These studies also address a sense of new meaning for participants, yet this was woven into other themes and was not a prominent aspect of the findings. This may have been due to the nature of acquiring a facial disfigurement through head and neck cancer, unlike the participants of the present study who accidentally acquired a facial disfigurement due to one horrific moment that changed their face forever.

Overall, these findings add to the knowledge of what accidentally acquiring a disfigurement is like for individuals and how they experience their identity throughout this difficult process. The current research has created more in-depth themes, which separate the

face and its links to identity along with highlighting participants' experiences. This is through incorporating an additional theme that focuses on the face and identity through expression, internalising society's reactions to the face and the separation of mind and body. Along with this, the current research focuses on facial disfigurement as a result of an accident rather than the cause of head and neck cancer.

Overall, this research set out to address the question, 'How does accidentally acquiring a facial disfigurement affect the perceptions, perspectives and experiences of identity for individuals?' The findings from this research showed that accidentally acquiring a facial disfigurement clearly had a huge impact on one's sense of identity and offers an in-depth understanding of this process.

Limitations of Research

One limitation of this research is that, as the researcher, my experience, and therefore my interviewing techniques, are limited in scope. This could have meant that my interviews did not go into as much depth as they could have done. Even though I have experience with seeing clients who have accidentally acquired a facial disfigurement and have conducted much research in this area, I quickly learned that qualitative research and interviews require a very different set of skills that need to be developed and learned through practice.

In addition, I struggled with the sensitivity of my topic as I wrote my analysis. Knowing my participants may read this research made me very cautious about what I was writing. I am, and was, an outsider who only saw a very small snapshot of their lives and only heard recollections of their experiences. I did not know them before, during or immediately after they accidentally acquired their facial disfigurement; I was meeting most of them years

after the incident and only for around an hour or two in total, making it more difficult to get a realistic idea of the participants and their experiences. This was most difficult when writing my analysis, as I reflected on and exposed my interpretation of these participants' unique experiences. As a new researcher, one becomes overly cautious of ethics and desperately keen to ensure participants are not affected through the process of conducting research. Yet, I feel we go through a process of learning in order to trust that the participants know their limits and are well aware that they may stop the interview or pass on any questions they do not wish to answer. This is a limitation of my research, as it meant I tried to be kind to my participants, not wanting to do them an injustice as they had kindly volunteered to take part.

These double hermeneutics are mostly tricky in this particular research, as not only am I a researcher interpreting other individuals experiences, I am also an 'outsider who does belong'. Having not had the experience of accidentally acquiring a facial disfigurement not only makes me an outsider, it also makes me someone who is not shunned by society for looking different. This is a huge factor that may have impacted on my results, as explored in the theme 'outsider after once belonging'. Overall, this dynamic between researcher and participant may have been fuelled with confusion and possibly anger, as these participants had no idea what I looked like prior to our interview, nor did I disclose that I had no visible difference.

Therefore, they may have assumed that, due to the nature of my research, I had experienced something similar to them, only to find out later that I had not. This could have led to participants emotionally and cognitively withdrawing from me, showing passive aggression towards me and possibly wanting to protect me from their difficult experience that they may felt I would not be able to understand or handle their pain.

In terms, of recruitment, some of my participants may have felt obligated to take part in my research as it was advertised by Changing Faces. Using this charity may have meant that some participants wanted to give back to the charity for the support they received in some way, or may even have felt that taking part meant they were able to receive support more rapidly. Likewise, many friends and family members of people who had experienced gaining an altered appearance follow Changing Faces on social media, and participants may have been encouraged by others to take part in my research. One participant in particular, mentioned that her mother had seen my post online and had said she should take part as 'it may be good for her'. This assumption may have meant that participants could have taken part but may not have been fully committed. Therefore, they possibly did not give me as much input as they could have done and were there to show others that they were working through their difficulties or supporting the cause. This limitation created difficulties for me as a researcher as I felt a need to justify why my research was valuable; but it also meant that I made it very clear that participants could withdraw if they wanted, which could have created a slightly unwelcoming feeling and a distant 'researcher-participant alliance'.

Some further limitations of my sample occurred as a result of recruiting from Changing Faces as all participants had counselling from the charity prior to my interviews. This would have had a huge impact on how participants view their altered appearance and identity. Along with this factor age and ethnicity may have also had an impact on these results as shown through Tara who was the youngest, leaving school and attending a new environment where no one knew her before her alter appearance helped her come to terms with and accept her new face. Participants ethnicity may have also acted as a limitation to

these results as some cultural values and beliefs can have a deep-rooted effect on how one views their identity and accidentally acquiring a facial difference.

Finally, I was limited by my sample size as it only consisted of six participants and the types of disfigurements were varied. Although my reasons for using a small sample were justified in the Methodology chapter, there are limitations within this.

Therefore, these findings cannot be generalised to all individuals who live with an accidentally acquired facial disfigurement. However, using a small sample size allowed me as a researcher to engage in an in-depth analysis of the data gathered. The sample was also varied in types of disfigurement, which is the most important part of each individual's experience, although I attempted to keep my sample as homogeneous as possible via using only accidentally acquired facial disfigurement. I did not include participants with the same cause of accidentally acquired facial disfigurement due to the restrictions in recruitment and time. It could also be argued that Cienna's visible difference may be experienced differently as it was the result of her wanting to enhance her beauty rather than an car accident or traumatic event. This limitation changed my results considerably as each experience was heavily dependent on the types of disfigurement, as was explored in the Analysis chapter.

Reflexivity

Methodological Reflexivity

Using public involvement to conduct this research meant that these findings came from participants who lived through these experiences first hand, giving us better insight into

the lived experiences of accidentally acquired facial disfigurement. Specifically to this study participants involvement meant giving a voice to the voiceless, sharing their valuable experience that we currently lack knowledge and insight on. Some participants also viewed their involvement as a way of giving back to a cause they are passionate about, yet, this may have been a limitation as they may have felt an obligation to take part.

I felt that some participants were possibly looking out for me as one said she had to with her friends and family. This adds an additional complexity to processing the loss of her old self, as she is dealing with looking fine on the outside for her friends and family, who struggle with seeing her new face. Was she portraying everything positively to me, as she was used to doing for those around her? Knowing this, I was extremely cautious with her, coating our interaction with lots of positivity. I tried to show that I was comfortable looking at and hearing her, so that she did not feel the need to look after me. Overall, this meant it was difficult for us both to escape this collusion.

As a new researcher who is inexperienced in applying a qualitative approach, specifically to interpretative phenomenological analysis, this played a huge role in the research process. I remember feeling anxious as my first interview was approaching, as I was worrying about whether participants would have much to say about their experiences. More importantly, I was worried about whether I would be able to pull out experiences of their identity as this is a very vague and complex phenomenon. I had to find ways of indirectly exploring their underlying thoughts on their identity, which I did through listening intently to cues relating to parts of their identity. However, this may have sometimes distracted me from their story. Another difficulty I faced as a counselling psychology trainee was not to create a therapeutic dialogue but be able to take myself out of being a therapist and find myself as a researcher. My supervisors helped with this difficulty, as they had noticed that my first

interview seemed very ‘nice’. I was trying very hard to form a good rapport with the participants, which made both my job as researcher and getting to more difficult parts of her experience harder.

As I continued on my research journey, I developed ways of getting clients to talk about their identity and noted what was most useful as I went along. When I began interviewing, I was overthinking ways of getting us to talk about the shift in identity, or no potential changes in their identity, yet I found that simply reflecting on important parts of their narrative sometimes had a greater impact and got participants on to a deeper level of reflection on the self.

It is crucial to note the inevitable power imbalance that occurred between me and my participants. I was responsible for setting boundaries as I was not their therapist, along with decisions like when to ask questions or when to end the interview. This became easier over time and, as I conducted more interviews, I felt more comfortable balancing the dynamic roles this training requires between student, clinician and researcher. My reflective journal played a huge role in the ease of this transition from student to researcher, as I used it to explore parts that I struggled with in previous interviews and the unconscious dynamic that played out between me and the participants.

An example of this can be seen through one participant in particular. I felt a high level of expectation in her talk; my impression was that she saw our interview as a test that she wanted to do well in. Eager to be the model participant, she tried to live up to my expectations by providing me with the answers she thought I was looking for. For example, she kept referring back to my study and what she had read in my information sheet. She

attempted to please me by telling me what she thought I wanted to hear, by showing me that there was a change in herself due to the accident.

Also in relation to this power imbalance, as discussed in the limitations section, the fact that I have not accidentally acquired a facial disfigurement also impacted on the dynamic between interviewer and interviewee. As I was part of the 'other', being the rest of the society that excluded my participants, this meant that aggression towards the 'other' was also directed towards me. This was sometimes a difficult dynamic to come out of, but it was very important for me to be able to reflect on the possibilities of feeling intimidated by this judgement in order to ensure that I treated this issue with sensitivity.

For all of my participants bar one, the interviews acted as a reflective journal: retelling their recollections of their accidentally acquired disfigurement and comparing themselves to where they are now. Some of the participants admitted that it is something they forgot and should remember more. One participant, however, used the interview as a way of expressing her anger at the incident and the huge impact it has had on her life. This sometimes felt like an attack on me, being classed as one of the 'others', those who have not accidentally acquired a disfigurement; it could even have been anger and jealousy towards those who were born with an altered appearance and have learned to live with it or who have had more understanding due to common knowledge on their conditions. She, however, felt her visual difference was unique and unheard of.

Personal Reflexivity

Having spent more time with this client group through this research, I believe this has significantly impacted on my clinical practice. It has enabled me to become more aware of the

numerous difficulties that many encounter when accidentally acquiring a facial disfigurement an how profound these can be. One important factor I will take into my clinical practice is the importance of the story and how much this retelling can be highly therapeutic and help me as a therapist get deeper insight into their psychological difficulties and coping mechanisms.

As I passionately wrote about the meaning of life for my participants, I reflected and wondered about what the 'meaning of life' meant for me. This led me to consider my here and now and my purpose for this particular research. My only desire for this important piece of work was simply that it would be meaningful and that it would give this group of individuals a voice in which to share their unique experiences. As I draw towards the end of this chapter, I look over these themes and this analysis hoping I have done these participants justice with regard to their experiences, their hardships, their admirable strength, and their willingness to openly share their experiences with me. Most importantly, I hope that I have provided a unique insight into who they are and how this experience has shaped their identities.

As I embarked on this journey and set out to make these voices heard, I discovered my own voice. For a long time, I wondered why I struggled to be my complete authentic self during my training. I then began to realise that I was entering a field in which I felt like a minority based on class, age, race and religion. Instead of being vocal and openly reflective about my differences at university, I noticed that I used other avenues to express these important parts of my identity. Through the process of this research and by studying identity, I am more aware of my differences and how these played out in my clinical work. I started to see these as my biggest strength rather than hiding that I am also an outsider in an environment in which I do not belong.

Similarly, to these participants, I experienced feelings of not belonging because I did not understand some aspects of the common culture surrounding me. Nor did I feel I was invited to celebrate and work through my unique differences. How I could support clients who were from marginalised groups to explore their identity if I covered up parts of my own. Therefore, this research topic helped me through this journey of understanding of my own personal identity and how I manage it professionally. Like my participants, I had to unpack and integrate all these aspects of my identity, being a young, working-class, African/Asian, Muslim woman.

Implications for Counselling Psychology Practice

This research offers a unique insight into how individuals who have accidentally acquired a facial disfigurement experience and perceive their identity. It highlights the complexities of accidentally acquiring a facial disfigurement and the need for providing well-adjusted counselling and psychotherapy specifically tailored to this unique group.

These findings suggest ways that counselling psychologists may approach the treatment for this client group. I have highlighted the core complexities experienced by these individuals, namely loss of self, social exclusion, and adapting to their new face and identity. Through establishing the struggles that these individuals encounter, we can begin to form treatment methods best suited to this client group.

It may be valuable to use these findings to improve training, so that professionals are better equipped to manage working with individuals with accidentally acquired facial disfigurements. In particular, a key finding of this research is that all individuals felt excluded from society and socially isolated themselves for months or even years after their accident.

This resulted in a number of social, physical and psychological difficulties, and may also be an obstacle to accessing psychological support. All participants were treated by their hospital and GP, but they were not always offered psychological support.

However, these difficulties with social isolation suggest that it may be useful to consider offering these individuals some form of group support, as they all longed for a sense of belonging and acceptance. Jaspal (2012) argued that support groups offer clients a non-stigmatising, non-judgemental, safe environment in which to share and explore their experiences. Notably, this is not suitable for all individuals who may accidentally acquire a facial disfigurement as some may want to reject the idea of belonging to an already isolated group.

Overall, this research provides counselling psychologists with the types of difficulties that accidently acquiring a facial disfigurement may address. These include shame, loss of the old self, post-traumatic stress disorder, stages of grief, a sense of injustice, social exclusion, complexities of integrating the old and new identity, loneliness and social isolation. There has been no clear treatment method for working with trauma for accidentally acquired facial disfigurement. However, cognitive behavioural therapy has been implemented for psoriasis, which focused on patterns of unhelpful beliefs and their impact on mood and behaviour (Muftin, 2012).

Thompson (2009) developed a step care model that emphasised access to self-help for the delivery of psychosocial interventions within dermatology. However, with more research and deeper understanding of this unique topic, counselling psychology would be best suited

to supporting individuals with the multiple complexities linked to acquired facial disfigurement.

Validity of this Research

As examined in the Methodology chapter, Yardley's (2000) criteria for assessing the validity of qualitative research was used to establish principles for evaluating the validity of this research. I will now discuss how they have been demonstrated here.

Sensitivity to context has been demonstrated through the thorough literature review conducted in Chapter 2. This review gave a wide-ranging look into the broad topic of facial disfigurement followed by a closer look into research specifically on accidentally acquired facial disfigurement to phenomenology, and the links between the face and identity. Therefore, the analysis is sensitive to the research context through thoroughly exploring the theoretical and empirical literature connected to the research area and has also ensured sensitivity for the data provided by these six participants. This research has also addressed these criteria by displaying reflexivity throughout my analysis, methodology and now discussion, showing that I have considered the feelings of my participants at every stage of the research process.

Commitment has been shown via my extensive reading around this topic and IPA, along with my history of working with and researching facial disfigurement. **Rigour** was also shown throughout this research as it adopts an IPA approach. This requires an in-depth engagement with the data collected in order to create emergent, superordinate and sub-themes.

Transparency was shown through the detailed account of the methodology used, and of the different stages of the analysis (see Chapter 2). Each section has been clearly presented throughout the Analysis chapter, theme headings have been clearly presented, and the interpretations have been evidenced by direct quotes from the interviews with associated page and line numbers from transcripts. **Coherence** is clear, as the research aim and methodology used naturally fit together and follow each other through the research in a logical way.

Lastly, **impact and importance** are the ultimate tests for validity. This research has shed light on a topic that has been neglected by counselling psychologists, as demonstrated by the lack of research in this field. The findings have emphasised why it is important for counselling psychologists to support individuals who go through a similar experience.

Suggestions for Further Research

Having worked with disfigurement for so many years prior to this research, I had not considered that participants had to adapt to change constantly as they developed, and with each surgery. Kiara expressed the struggle of not only having to adapt to this difficult change continuously throughout her recovery, but also having the challenge of having to reinvent who she was as a person, which was dependant on her external change following each surgery. When Kiara was asked if she felt there was a difference between congenital and

accidentally acquired disfigurement she replied: *'It's different when you're born with a disfigurement. You have your whole life to get used to it, but with an accidentally acquired disfigurement you're stuck between both worlds'* (Kiara, 6, 261–268). It could be interesting to research participants with congenital and acquired facial disfigurement and the notion of recreating oneself as congenital disfigurement individuals also encounter multiple surgeries: do they too undergo the struggle of integrating two selves, pre- and post-surgery?

Having conducted this research, and reflecting on the limitations it carries, it may be useful to conduct a follow-up study that includes participants with the same type of accidentally acquired facial disfigurement. For example, my participants included people who had survived burns, jet ski accidents, car accidents and disfigurements following a cosmetic procedure. This certainly had a huge impact on these findings as the cause of disfigurement played a huge role in each participant's experience. Hence, using a homogenous approach means that the research would be more accurate for a defined group, for whom the research problem has both relevance and personal significance.

As explored through one of my participants, cosmetic surgery is a growing field that, although it aims to enhance beauty, can sometimes result in severe disfigurement. Therefore, researching this topic through counselling psychology's in-depth approach would shed light on this neglected subject.

Another suggestion for further research on this topic is to adopt a different approach. For example, it may be interesting to explore participants' experiences during the initial aftermath of accidentally acquiring a facial disfigurement. Then again, some years later, it may be prudent to have more of an insight into their process of integrating their two selves. Although this research would be valuable and would give more insight into this crucial

journey these individuals go through, it may not be ethical to interview participants straight after their initial trauma.

Superordinate theme two, 'front seat of identity', is a crucial finding that could potentially be researched in depth. Through looking at these links between the face and identity closer, we can establish ways of supporting this group as we can further understand the difficulties they encounter with lack of expression, internalising being excluded once others see their facial disfigurement and how to support them to integrate the mind and body.

Finally, researching the use of counselling for these individuals would aid counselling psychologists further in creating suitable treatment methods for the complexities that come with accidentally acquiring a facial disfigurement. To elaborate, researchers could specifically analyse the way participants talk about the 'self' and how they view their identity through counselling.

Significance of this Research

This study's distinctive and original contribution lies in the fact that there has been a lack of research on the 'journey' of accidentally acquired facial disfigurement and its links to identity within the discipline of counselling psychology. As explored in the literature review, the research most similar to this has studied head and neck cancer patients who underwent treatment resulting in a change in facial appearance. Therefore, this study is the first to delve deep into the connection between accidentally acquiring a facial disfigurement and how this impacts parts of one's identity through a counselling psychologist lens.

Conclusions

Given the limited in-depth research on identity for individuals who have experienced an accidentally acquired facial disfigurement, this study used IPA to explore the in-depth experience of six participants and their perspectives, perceptions and experiences of their identity. This group is usually overlooked within this field and not heavily researched; along with this, the connection between the face and identity is mostly researched using participants who have undergone facial transplant surgery and mostly within philosophy or scientific research.

The findings gathered are consistent with current existing literature, although some new insights have surfaced from this study. Firstly, this research uncovers participants' journeys and the similarities with the stages of grief and mourning. This comparison is useful to be aware of when treating participants or creating new treatment plans for this group. Secondly, outlining participants' experience of acquiring a facial disfigurement, and its direct links to the face, allows us to understand the severity of accidentally acquired facial disfigurement to one's identity. This is significantly overlooked by many professionals as society focuses on 'fixing' one's face rather than acknowledging the extensive psychological impact that comes with this experience.

Through conducting this research, I hope that I have given these individuals a platform to safely share their experiences and have encouraged a growing number of voices within this field. I hope counselling psychology finds better ways of accessing and supporting these individuals with their expertise, and finally that more research is conducted on the issues around accidentally acquiring a facial disfigurement, so that we can begin to fully understand and support people who have suffered this traumatic and complex phenomenon.

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Appendix A: Recruitment Flyer

Appendix B: Social Media Recruitment

Twitter

Facebook

Instagram

Appendix C: Information Sheet

INFORMATION SHEET

Title of Research Project:

Looking inside the face – experiences of living with an accidentally acquired facial disfigurement and its perceived impact on identity; Interpretative phenomenological analysis

Brief Description of Research Project, and What Participation Involves:

Dear Participant

Please read the following information before deciding whether or not to take part in the above named research project.

INVITATION

You are being invited to take part in a research study looking into the experience of identity of participants who have accidentally acquired a facial disfigurement. Sania Manjlai, a counselling psychologist in training at the University of Roehampton, is undertaking this research study. Before you decide whether or not you wish to take part in this study, it is important for you to understand exactly what the research will involve. Please feel free to ask for further information about this research project, and what might be expected of you as a participant in this research prior to consenting to take part in the individual interview.

THE PURPOSE OF THIS STUDY

This phenomenological qualitative research aims to undertake an interpretative phenomenological analysis (IPA) to understand the experiences of people who have encountered an accidentally acquired facial disfigurement and how they construct their identity. A semi-structured interview will be held with each of the participants. It is hoped that the outcomes of this study may support future counselling psychologists' who work with facial

disfigurement by providing insight into gaining an accidentally acquired facial disfigurement and how it may impact one's identity.

Taking part is also a unique opportunity to reflect on experiences and allow a platform to voice any thoughts. At this stage of the study, we need to carry out interviews with 6 – 8 individuals with an accidentally acquired facial disfigurement. Interviews will take place at the Changing Faces premises or at an agreed venue. Interviews are audio recorded and take up to one hour.

ELIGIBILITY FOR INCLUSION INTO THIS STUDY

This study will include women who have encountered an accidentally acquired facial disfigurement within the past five years. The intended sample size will be 6-8 participants, aged between 18 and 65, who were not born with a facial disfigurement but acquired it as an adult.

Sometimes talking about or recalling experiences can feel upsetting or distressing. Therefore, all participants will be given a telephone call before taking part to ensure they will be able to handle the interview process. Participants will be asked questions about their disfigurement and mental health history.

RISKS INVOLVED IN PARTICIPANTING IN THIS STUDY

If at any point you find participating in this interview distressing, you can choose to withdraw from the study. If after the interview has taken place, you would prefer your information not to be included in this study, you can withdraw your consent without the need to provide any reasons. Please note, that if you choose to withdraw your consent once the research study has been completed, your data may be used in a collated form. Please note that some data will be stored for at least ten years.

If taking part in the interview cause you distress, you may wish to speak further with either the researcher (who can arrange to give you information on relevant listed support agencies) or alternatively, you can speak with an independent party, the Director of Studies, or Head of the Psychology department whose contact details are provided herein.

If for whatever reasons you are not happy with how this research has been conducted, or if you have serious concerns about this research project, then you are free to contact the Director of Studies or Head of the Psychology department whose contact details are provided below.

CONFIDENTIALITY AND ANONYMITY

All interviews will be digitally **recorded** and then **transcribed.** The digital recordings will be securely stored on a password-protected computer and then subsequently destroyed once they have been transcribed. Your interview will be transcribed, your identity will be anonymous, and all identifiable details will be removed from your transcript. All transcripts will then be encrypted and stored securely on a password-protected computer at the researchers home.

PROPOSED USE OF RESEARCH FINDINGS

Research findings will be used in the researcher's thesis or they may be used later in the form of an academic paper or published journal.

Investigator Contact Details:

Sania Manjlai
Department of Psychology
University of Roehampton
London SW15 4JD
Email: **manjlais1@roehampton.ac.uk**
Telephone:

Appendix D: Consent Form

University of Roehampton London

PARTICIPANT CONSENT FORM

Title of Research Project:

Looking inside the face – experiences of living with an accidentally acquired facial disfigurement and its perceived impact on identity; Interpretative phenomenological analysis

Brief Description of Research Project, and What Participation Involves:

Dear Participant

Please read the following information before deciding whether or not to take part in the above named research project.

INVITATION

You are being invited to take part in a research study looking into the experience of identity of participants who have accidentally acquired a facial disfigurement. Sania Manjlai, a counselling psychologist in training at the University of Roehampton, is undertaking this research study. Before you decide whether or not you wish to take part in this study, it is important for you to understand exactly what the research will involve. Please feel free to ask for further information about this research project, and what might be expected of you as a participant in this research prior to consenting to take part in the individual interview.

THE PURPOSE OF THIS STUDY

This phenomenological qualitative research aims to undertake an interpretative phenomenological analysis (IPA) to understand the experiences of people who have encountered an accidentally acquired facial disfigurement and how they construct their identity. A semi-structured interview will be held with each of the participants. It is hoped that the outcomes of this study may support future counselling psychologists' who work with facial

disfigurement by providing insight into gaining an accidentally acquired facial disfigurement and how it may impact one's identity.

Taking part is also a unique opportunity to reflect on experiences and allow a platform to voice any thoughts. At this stage of the study, we need to carry out interviews with 6 – 8 individuals with an accidentally acquired facial disfigurement. Interviews will take place at the Changing Faces premises or at an agreed venue. Interviews are audio recorded and take up to one hour.

ELIGIBILITY FOR INCLUSION INTO THIS STUDY

This study will include women who have encountered an accidentally acquired facial disfigurement within the past five years. The intended sample size will be 6-8 participants, aged between 18 and 65, who were not born with a facial disfigurement but acquired it as an adult.

Sometimes talking about or recalling experiences can feel upsetting or distressing. Therefore, all participants will be given a telephone call before taking part to ensure they will be able to handle the interview process. Participants will be asked questions about their disfigurement and mental health history.

RISKS INVOLVED IN PARTICIPANTING IN THIS STUDY

If at any point you find participating in this interview distressing, you can choose to withdraw from the study. If after the interview has taken place, you would prefer your information not to be included in this study, you can withdraw your consent without the need to provide any reasons. Please note, that if you choose to withdraw your consent once the research study has been completed, your data may be used in a collated form. Please note that data will be stored for at least ten years.

If taking part in the interview cause you distress, you may wish to speak further with either the researcher (who can arrange to give you information on relevant listed support agencies) or alternatively, you can speak with an independent party, the Director of Studies, or Head of the Psychology department whose contact details are provided herein.

If for whatever reasons you are not happy with how this research has been conducted, or if you have serious concerns about this research project, then you are free to contact the Director of Studies or Head of the Psychology department whose contact details are provided below.

CONFIDENTIALITY AND ANONYMITY

All interviews will be digitally **recorded** and then **transcribed.** The digital recordings will be securely stored on a password-protected computer and then subsequently destroyed once they have been transcribed. Your interview will be transcribed, your identity will be anonymous, and all identifiable details will be removed from your transcript. All transcripts will then be encrypted and stored securely on a password-protected computer at the researchers home.

PROPOSED USE OF RESEARCH FINDINGS

Research findings will be used in the researcher's thesis or they may be used later in the form of an academic paper or published journal.

Investigator Contact Details:

Sania Manjlai
Department of Psychology
University of Roehampton
London SW15 4JD
Email: manjlais1@roehampton.ac.uk
Telephone: **07786600559**

Consent Statement:

I agree to take part in this research and am aware that I am free to withdraw at any point without giving a reason, although if I do so, I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the researcher and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Name ……..

Signature ……

Date ……

Please indicate if you wish to receive a full transcript of your taped interview:

Yes, I would like to receive a copy of the interview transcript. ☐

No, I would not like to receive a copy of the interview transcript. ☐

Please indicate if you wish to receive a copy of the summarised results of the study:

Yes, I would like to receive a copy of the summarised results. ☐

No, I would not like to receive a copy of the summarised results. ☐

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the researcher, or contact the Director of Studies. However, if you would like to contact an independent party please contact the Head of Department.

If you wish to withdraw from the study, please contact the researcher with the ID number, which appears on the Debriefing Form. The data may still be used/ published in an aggregate form.

Director of Studies Contact Details:
Dr Rosemary Clare Rizq
Holybourne Avenue
Department of Psychology
University of Roehampton
London SW15 5PJ
r.rizq@roehampton.ac.uk
0208 392 3021

Head of Department Contact Details:
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Department of Psychology
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Appendix E: Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

Please complete the following:

Name: .....

Date of Birth: .....

Country of Birth: .....

Ethnicity.....

What year did you acquire a facial disfigurement.....

Did you have treatment for it, how long.....

Have you had any other difficulties since you acquired a facial disfigurement

.....

.....

Appendix F: Screening Questionnaire

University of Roehampton London

SCREENING QUESTIONS

Name……

Date of Birth ……

Do you live in the U.K? Yes ☐ No ☐

Fluent English Yes ☐ No ☐

Did you accidentally acquire your disfigurement between one and five years ago? If so, how long ago?

……..

What type of disfigurement do you have? How did you acquire your disfigurement?

……

……

……

Are you currently under any psychiatric care?

If so, could you share this with

me……

……

……

How would you describe your mental health?

……

……

Is there any reason you feel you may be uncomfortable answering certain questions that may be asked about your disfigurement or identity during the interview?

……

……

……

Thank you for your cooperation

Appendix G: Ethical Approval

Dear Sania,

Ethics Application
Applicant: Sania Manjlai
Title: Looking inside the face – experiences of living with an accidentally acquired facial disfigurement and its perceived impact on identity; Interpretative phenomenological analysis
Reference: PSYC 17/ 281
Department: Psychology

I am pleased to confirm that the risk assessment for your project has been reviewed and approved by the Health & Safety Office. Under the procedures agreed by the University Ethics Committee I am pleased to advise you that your Department has confirmed that all conditions for approval of this project have now been met. We do not require anything further in relation to this application.

Please note that on a standalone page or appendix the following phrase should be included in your thesis:

The research for this project was submitted for ethics consideration under the reference PSYC 17/ 281 in the Department of Psychology and was approved under the procedures of the University of Roehampton's Ethics Committee on 30.01.18.

Please Note:

- **This email confirms that all conditions have been met and thus confirms final ethics approval (it is assumed that you will adhere to any minor conditions still outstanding, therefore we do not require a response to these).**
- **University of Roehampton ethics approval will always be subject to compliance with the University policies and procedures applying at the time when the work takes place. It is your responsibility to ensure that you are familiar and compliant with all such policies and procedures when undertaking your research.**
- **Please advise us if there are any changes to the research during the life of the project. Minor changes can be advised using the Minor Amendments Form on the Ethics Website, but substantial changes may require a new application to be submitted.**
- **If this project involves clinical procedures or administering substances it is a condition of Ethics approval that all relevant SOPs published on the department communities pages are fully complied with.**

Many thanks,

Jan

Appendix H: Interview Schedule

University of Roehampton London

INTERVIEW SCHEDULE

As this study is using a qualitative analysis, the following questions are merely a basis for a conversation and are indicative of the broader subject area that will be explored during the interview. These questions are not fixed and participant responses may lead to new areas of interest.

Participants are reminded that if at any stage they feel uncomfortable or distressed, or wish to stop talking about a particular topic, they have the right to not respond to a question or to stop the interview.

Indicative questions

1) Would you feel comfortable telling me your story? How did you experience acquiring a facial disfigurement?
2) What was going on in your mind then?
3) How would you describe yourself as a person? prompt: What sort of person are you? Most important characteristics: happy, moody.
4) Has acquiring a facial disfigurement made a difference to how you see yourself? prompt: If so, how do you see yourself now as different from before you accidentally acquired a disfigurement? How would you say you have changed/not changed?

Further Prompts

1) What does the term 'disfigurement' mean to you? How do you define it?
2) How do you feel about your disfigurement now? prompt: physically, emotionally, mentally
3) How does acquiring a facial disfigurement affect your everyday life? prompt: work, interests, relationships.
4) If you had to describe what your disfigurement means to you, what would you say? prompt: What words come to mind, what images? Do you have a nickname for it?

5) What about the way other people see you? prompt: members of your family, friends?

6) Do you see yourself as being disfigured? prompt: always, sometimes? Would you say you were an ill person?

7) On a day-to-day basis, how do you deal with having a disfigurement? prompt: do you have particular strategies for helping you? ways of coping, practical, mental.

8) Do you think about the future much?

Appendix I: Debrief Form

University of Roehampton London

DEBRIEFING FORM

Interview: *Looking inside the face – experiences of living with an accidentally acquired facial disfigurement and its perceived impact on identity; interpretative phenomenological analysis*

Thank you very much for your participation!

ID number: 001

If you have any questions regarding this study or If you wish to withdraw from the study, please contact the researcher with the ID number above. The data may still be used/ published in an aggregate form

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You are reminded that at any stage of this research you are free to withdraw, using the anonymous identification number which you have been given during this debriefing session. Please contact me via the below contact details should you decide to withdraw and I will ensure you audio-recording is deleted. However, please note if you wish to withdraw once the report has been written, your data may still be used in its collated and anonymised form in the published work.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the researcher or contact the Director of Studies. However, if you would like to contact an independent party, please contact the Head of Department (contact details below). If you found this experience distressing

in any way and would like additional support please contact the support service of your organisation, the BPS (http://www.bps.org.uk/bpssearchablelists/ropsip) , or the NHS (http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/Free-therapy-or-counselling.aspx).

Support services:

Burn Centre Care - 01924.212.332 , email: info@burncentrecare.co.uk

Changing Faces – 0345 450 0275, email: info@changingfaces.org.uk

Dans Fund For Burns - 020 7262 4039, email: info@dansfundforburns.org

Let's Face It – 01843 491291, email: chrisletsfaceit@aol.com

Saving Faces - 020 8223 8049, email: info@savingfaces.co.uk

The Katie Piper Foundation - 020 7420 7813, email: ezinna@katiepiperfoundation.org.uk

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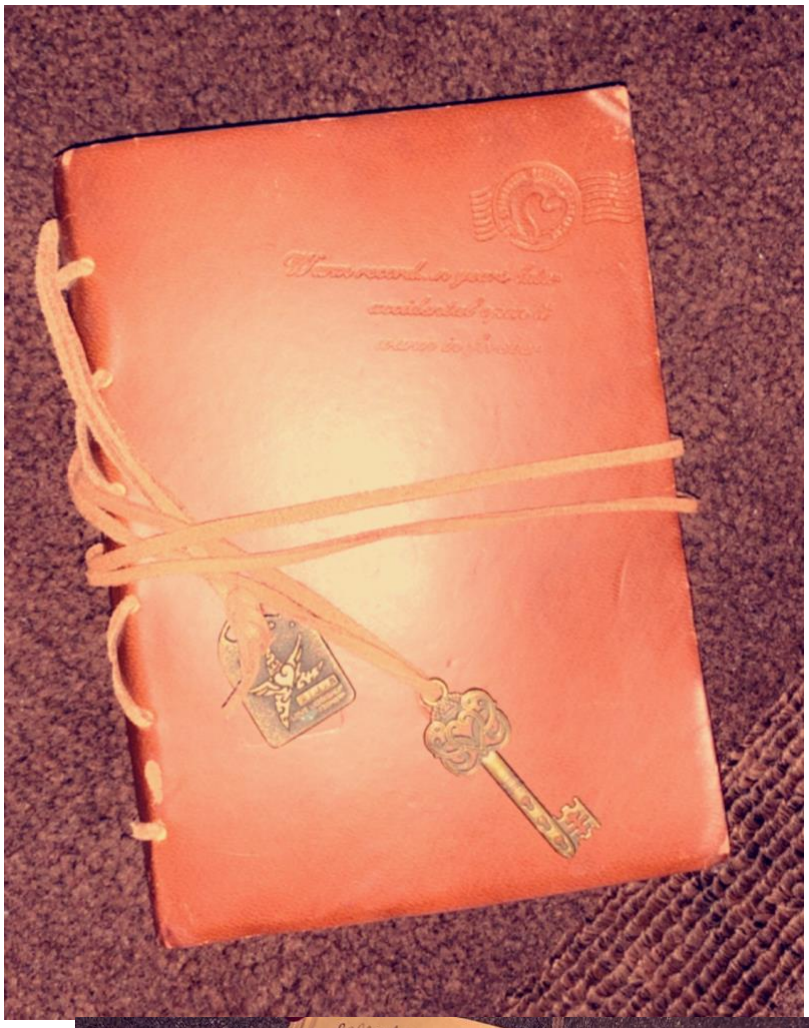
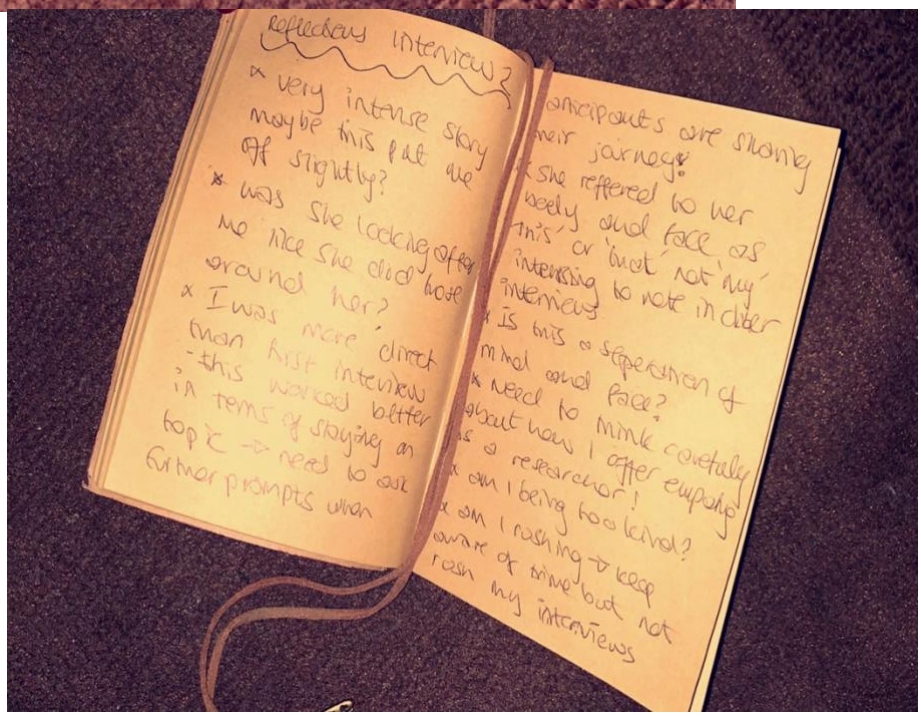
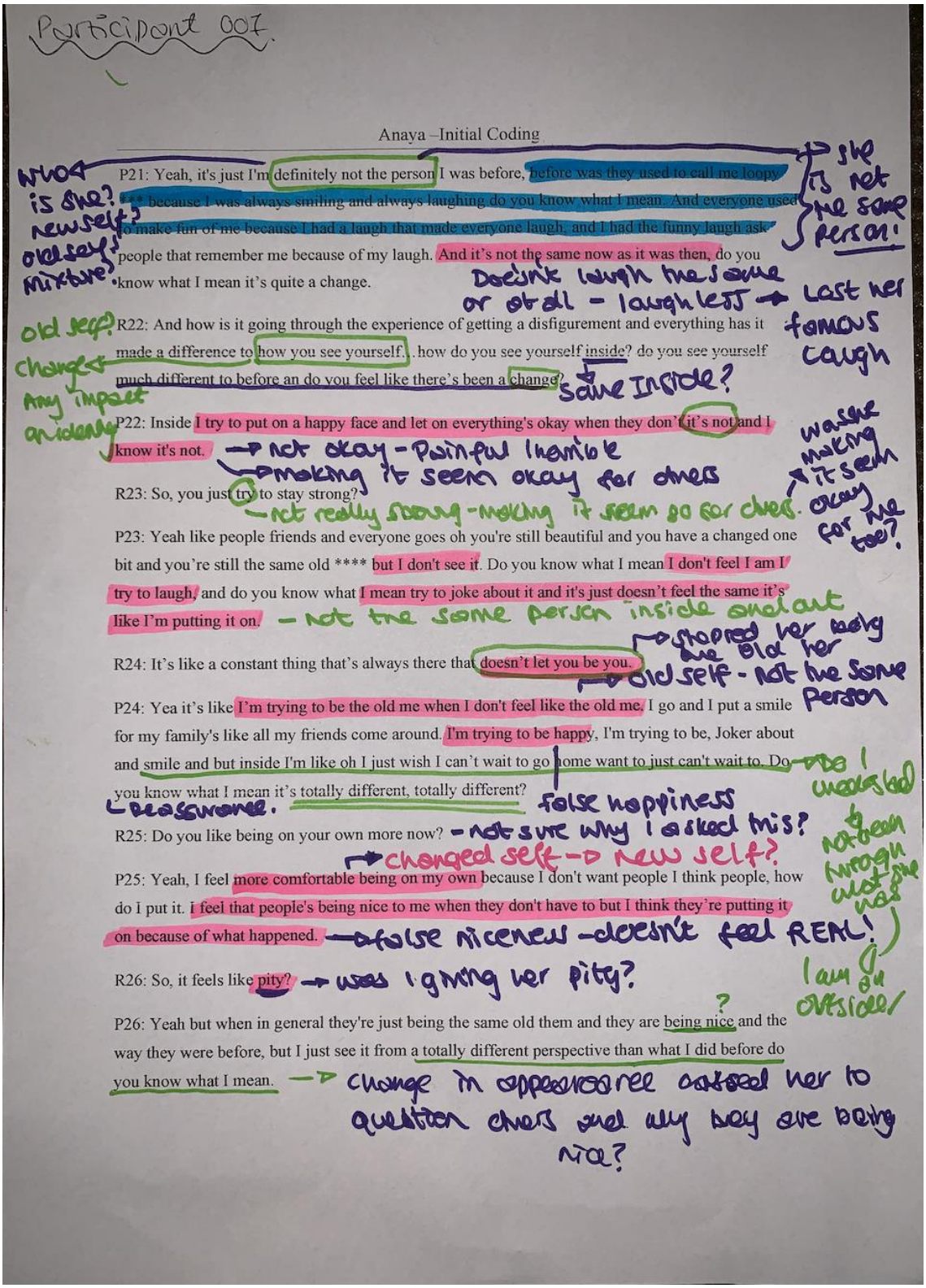
Appendix J: Reflective Journal





Appendix K: Annotated Transcript Example



Participant 007.

Anaya –Initial Coding

P21: Yeah, it's just I'm definitely not the person I was before, before was they used to call me loopy **** because I was always smiling and always laughing do you know what I mean. And everyone used to make fun of me because I had a laugh that made everyone laugh, and I had the funny laugh ask people that remember me because of my laugh. And it's not the same now as it was then, do you know what I mean it's quite a change.

R22: And how is it going through the experience of getting a disfigurement and everything has it made a difference to how you see yourself... how do you see yourself inside? do you see yourself much different to before an do you feel like there's been a change?

P22: Inside I try to put on a happy face and let on everything's okay when they don't it's not and I know it's not.

R23: So, you just try to stay strong?

P23: Yeah like people friends and everyone goes oh you're still beautiful and you have a changed one bit and you're still the same old **** but I don't see it. Do you know what I mean I don't feel I am I try to laugh, and do you know what I mean try to joke about it and it's just doesn't feel the same it's like I'm putting it on.

R24: It's like a constant thing that's always there that doesn't let you be you.

P24: Yea it's like I'm trying to be the old me when I don't feel like the old me. I go and I put a smile for my family's like all my friends come around. I'm trying to be happy, I'm trying to be, Joker about and smile and but inside I'm like oh I just wish I can't wait to go home want to just can't wait to. Do you know what I mean it's totally different, totally different?

R25: Do you like being on your own more now?

P25: Yeah, I feel more comfortable being on my own because I don't want people I think people, how do I put it. I feel that people's being nice to me when they don't have to but I think they're putting it on because of what happened.

R26: So, it feels like pity?

P26: Yeah but when in general they're just being the same old them and they are being nice and the way they were before, but I just see it from a totally different perspective than what I did before do you know what I mean.

Appendix L: Emergent Theme Table

Emergent Themes (Kiara)	Quote	Transcript Location
Accepting pain	*(Kiara, 9, 427-428)*	*'I made peace with pain, they couldn't do that"*
Different Selves	*(Kiara, 6, 286-287)*	*'There's the pretty side to it (the healing over time), the ugly side to it and then the accepting side'*
Protecting others pain	*(Kiara, 9, 419)*	*'They were dealing with my scars, so I will deal with their pain'*
Protecting her pain	*(Kiara, 3, 109-110)*	*'it's not just for you it's for your family for society...being society does give you a hard time when you go out there with your scars',*
Whose face am I wearing?	*(Kiara, 5, 250-256)*	*'The old me died in the fire...even when I look at old pictures, I don't recognise myself'*
Identifying with exclusion	*(Kiara, 1, 78-79)*	*'Everyone's going to hate me, no one's going to come near me, they'll think it's contagious '*
Distant from body – Separation	*(Kiara, 5, 215-218)*	*"It's tough to live in a skin that you're not familiar with, because it's constantly changing… I think this is the sixth neck Me: I notice you call it different necks not my neck, is its distant to you, yes yes"*
Accepting both selves old and new	*(Kiara, 5, 215-218).*	*'I have two selves, the old me and the new me'*